Screening For Success: Evaluating Reliability For A Screening Tool For Fetal Alcohol Spectrum Disorder In Adulthood

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Abstract

Structured for Success Project (SFSP) is a community health initiative in Prince George, British Columbia, that offers services to parents who may be affected by fetal alcohol spectrum disorder (FASD). SFSP developed a screening tool based on the primary and secondary characteristics of FASD. Moderate construct validity was indicated for the Primary Characteristics subscale. Psychometric properties of the screening tool, based on 65 completed screening tools, revealed satisfactory item statistics and alpha estimates of .843 for the Primary Characteristics subscale and .854 for the Secondary Characteristics subscale. The scores produced from the rating scale categories were found to be working as expected based on a Rasch analysis. Test-retest stability reported significant results: for the primary characteristics, $r^2 = .768, p < .001$ and for the secondary characteristics, $r^2 = .708, p < .001$. In general, the SFSP screening tool was found to be a reliable measure for assessing FASD characteristics.
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Chapter One
Introduction and Overview

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe permanent birth defects caused by maternal consumption of alcohol during pregnancy. This umbrella term includes diagnostic criteria, such as fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), alcohol related birth defects (ARBD), and alcohol related neurological defects (ARND). The term FASD will be used throughout this paper to include the many complexities and diversities of this disorder. FASD is the most common cause of mental retardation in the Western World (Astley, 2003). Individuals with FASD endure lifelong physical, intellectual, cognitive, and behavioural disabilities. These disabilities are often compounded by secondary emotional and behavioural disabilities such as low self-esteem, depression, school failure, and criminality, especially when the syndrome remains undiagnosed (Astley & Clarren 2000). These disabilities come at a high cost to individuals, families, schools, judicial systems, and medical and mental health systems, yet services designed for the specific needs of people who have FASD are almost non-existent.

Many adults who are affected by FASD go undiagnosed and most have problems of functioning in their daily lives. They have elaborate needs that most often are poorly or rarely identified. Failure to address these needs leads to adults who “fall through the cracks” of the health and social service system. When adults with FASD become parents, there is an abundance of skills and abilities that are largely lacking. The challenges of everyday parenting can become overwhelming for these parents and, in some cases, can lead to having their children removed from their care and placed in foster homes. Not only
do these parents face challenges raising their children, but they also face additional problems such as poverty, lack of education, lack of job skills, and lack of adaptive functioning skills. Researchers have suggested that, although there are many other parents who have similar difficulties, FASD affected parents have cognitive and adaptive skill limitations as well as increased emotional vulnerabilities that seem to put them at higher risk for experiencing difficulties in their parenting role (Ladue, Schacht, Tanner-Halverson, & McGowan, 1999; Rutman, LaBerge, & Wheway, 2002; Streissguth, Barr, Kogan, & Bookstein, 1996). Streissguth and O’Malley (2000) stated: “Patients with FASD function best in settings where life is predictable and structured, expectations are clear and reasonable, they are treated with respect and understanding, and they have appropriate role models” (p.185). Understanding the complexity of the needs of parents affected by FASD is essential for service providers to be able to provide structured and predictable environments for parents to parent successfully.

Rationale for Studies

There is an extensive collection of research done on FASD in children; however, 30 years have passed since teterogenic effects of alcohol were first recognized and there are now two generations of children affected by FASD who have reached adulthood. Adults affected by FASD experience the life-long consequences of birth defects; these birth defects can have profound effects on functional integrity because the primary locus of these birth defects is the brain (Streissguth & O’Malley, 2000). The disabilities that individuals can face include, but are not limited to, problems with memory, abstract reasoning, changing modalities, sequencing, generalizing information and slower cognitive pace. In addition, researchers have proposed that the most challenging area for FASD patients is
adaptive functioning. Adaptive functioning refers to, but is not restricted to, daily living skills, socialization skills, and motor skills (Rutman, LaBerge & Wheway, 2002).

Several adaptive functioning scales have been developed; the most widely used is the Vineland Adaptive Behaviour Scale. This scale, and others like it, measure adaptive functioning but were not formulated for individuals with FASD. Only a psychologist can administer and interpret these types of tests, and in most cases, it is simply not feasible for service providers to access these measures. Therefore, to serve parents who may be affected by FASD, it is essential that paraprofessionals have a screening tool available to assess what interventions are appropriate and what environmental accommodations need to be made and, also, to support the referral process for a complete diagnosis of FASD.

The treatment of people who are affected by prenatal alcohol exposure continues to be complicated by the lack of an appropriate screening and diagnostic formulation. Chudley, Conry, Cook, Loock, Rosales, and LeBlanc (2005) reported that there were currently no standardized screening tools available in Canada. Because of the lack of standardized measures, a team of professionals in Prince George, British Columbia, developed a tool to screen for possible FASD in parents. The screening tool is used for entry purposes in the Structured for Success Project. The Structured for Success Project began operating in December of 2004, as a pilot project funded by the Ministry of Children and Family Development. The project involves a multidisciplinary team that offers services to families who may be affected by FASD. The Structured for Success Project is a family support program designed to provide services to identified parents whose adaptive functioning and parenting capacity have been compromised by a combination of suspected or diagnosed FASD. The SFSP is a collaborative initiative between the Northern Health

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Authority, Intersect Youth & Family Services Society, Ministry for Children and Family
Development, Prince George Native Friendship Centre, the Northern Health Adult Mental
Health Services, and the Northern Health Addictions. These agency partners came together
to form a multidisciplinary team with the capacity to provide comprehensive, community-
based services. The SFSP recognizes that non-traditional intervention methods are required
to meet the complex needs of families for whom historical approaches have been
unsuccessful. Please see Appendix A for the Structured for Success Project overview. I
have been an employee with the Structured for Success Project since December 2004, as a
family worker. As an employee, I have access to the screening tools for data collection
while maintaining confidentiality of the parents.

This study will determine the degree of reliability of the Structured for Success
Project screening tool.

Aim of the Present Studies

The purpose of this study is to determine the psychometric properties of the scores
produced by the Structured for Success Project screening tool. The purpose of the SFSP
screening tool is to determine program entry to the Structured for Success Project in Prince
George, British Columbia, and to identify individuals who may require a referral for a
diagnosis of FASD. The objectives are:

1. In Study 1, to evaluate the construct validity of the SFSP screening tool.

2. In Study 2, to test for internal consistency of the SFSP screening tool and to test the
   rating scale categories.

3. In Study 3 to test for test-retest reliability of the SFSP screening tool.
Literature Review

*What is Fetal Alcohol Spectrum Disorder?*

Prenatal exposure to alcohol can have detrimental effects throughout the life span; different combinations of factors may interact causing varying degrees of organic dysfunction in individuals. The primary concern is brain damage which can cause deficiencies in cognitive functioning, including memory, learning problems, attention deficits, poor motor coordination, and difficulties with problem solving (Autti-Ramo, 2002). These cognitive deficiencies create long-standing problems in several areas of life, including school, work, and social relationships (Connor & Streissguth, 1996). Paul Lemoine from Nantes, France, published a report about children born to alcoholic mothers; his research found features and behaviours that are now determined to be characteristics of FASD (Lemoine, Harrousseau, Borteyru, & Menuet, 1968). In 1973, Kenneth Jones and David Smith, dysmorphologists, identified “a similar pattern of craniofacial, limb, and cardiovascular defects associated with prenatal onset growth deficiency and developmental delay” in eight unrelated children born to chronic alcoholic mothers (Jones, Smith, Ulleland, & Steissguth, 1973, p.1267). In a second report, three more infants were recognized, and the first necropsy on such a patient disclosed serious dysmorphogenesis of the brain; the authors thought that this dysmorphogenesis might be responsible for some of the functional abnormalities and joint malpositions seen in the syndrome. The naming of the disorder as Fetal Alcohol Syndrome (FAS) put the emphasis squarely on the presumed etiology. More recently, FAS has been defined by three criteria: (1) growth deficiency of prenatal origin for height and weight, (2) a pattern of specific minor anomalies that includes characteristic facial features, e.g. short palpebral fissures, thin upper lip, smooth
and/or long philtrum, and (3) central nervous system dysfunction, including microcephaly, delayed development, hyperactivity, attention deficits, and so forth (Kopera-Frye, Dehaene, & Streissguth, 1996).

*Terminology*

Many labels have been used to describe the effects of significant intrauterine alcohol exposure. Due to the variability and severity of the disorder, researchers have developed an umbrella term. Fetal Alcohol Spectrum Disorder (FASD) is the broad term that is given to describe individuals having specific patterns of physical anomalies, growth deficiency, and central nervous system (CNS) dysfunction, who are born to mothers who used alcohol during pregnancy (Streissguth & O’Malley, 2000). It is sometimes easier to think of the analogy of a color spectrum to understand FASD, rather than thinking of a disorder with clear guidelines for diagnosis. FASD has many faces, many abilities, and many disabilities. FASD is similar to the color spectrum in that you can clearly see the reds, greens, and blues of the color spectrum, but the ultra violet colors are not visible although they are, unquestionably, part of the color spectrum. Researchers have previously tried to organize these differences using several different terms, but essentially, they all have a common theme: maternal alcohol exposure during pregnancy that causes brain damage to some varying degree. Due to these complexities and varying degrees of disabilities, the umbrella term of FASD was established.

Researchers have previously used several terms in literature to describe prenatal alcohol exposure. Only a relatively small proportion of people prenatally affected by alcohol are diagnosed with FAS. The terms “fetal alcohol effects” (FAE) and “possible fetal alcohol effects” (PFAE) were introduced in the mid 1970s to describe patterns of birth
defects following significant prenatal alcohol exposure that do not include facial features or growth retardation seen in FAS (Abel, 1988). In addition, Sokol and Clarren (1989) proposed the category “alcohol-related birth defects” (ARBD) to focus primarily on the physical anomalies rather than the brain disturbances associated with severe prenatal alcohol exposure. The Institute of Medicine (IOM) (1996) suggested a new category to replace FAE; this classification was referred to as alcohol-related neurodevelopment disorder (ARND). ARND focuses specifically on the brain dysfunctions in the presence of significant prenatal alcohol exposure. FAS, FAE, PFAE, ARBD, and ARND are currently grouped under the term FASD. While many of these terms are currently used to describe individuals, researchers are recommending the use of the term FASD for consistency and accuracy of medical terminology.

Each term listed above displays varying degrees of difficulties for an individual. For example, individuals with FAE appear to suffer from damage to the central nervous system. This central nervous system damage results in a variety of learning and behaviour disorders, but does not result in a significantly lowered IQ (Sokol & Clarren 1989). As well, a diagnosis of FAE is more difficult to make and, in fact, may have to be inferred from knowledge of the mother’s drinking habits, combined with learning and behavioural difficulties exhibited by the individual (Streissguth, 1986). On the other hand, individuals with FAS have more physical deformities, such as heart malformations and facial anomalies. The brain dysfunctions of people with FAE/ARND are often as severe as, if not worse than, brain dysfunctions in people with FAS (Connor & Streissguth, 1996). Streissguth and colleagues (1996) identified primary and secondary disabilities of FASD. The primary disabilities are associated with differences found in the brain structure and
function such as, developmental dysmaturity, sensory integration problems, and difficulties with memory. The secondary disabilities are not intrinsic to the disorder, nor evitable, but are defensive behaviours that often develop over time because of chronic frustration, trauma and/or failure, reflecting a "poor fit" between the needs of the person and his or her environment (Malbin, 2000).

Although no alcohol-dose threshold is known to differentiate between FAS and ARND, the timing of alcohol consumption during gestation appears to be important. Drinking relatively early in pregnancy may lead to many of the facial anomalies seen in children with FAS, whereas the deleterious effects of alcohol on the brain can occur at any time during pregnancy (Connor & Streissguth, 1996).

**Prevalence of FASD**

Since the late 1970s, researchers have been studying the prevalence of FASD; however, this particular area of study has proven to be extremely difficult due to several factors; these factors include issues related to sampling, diagnostic criteria, and the coordination of interdisciplinary activities (May & Gossage, 2001).

Estimates of FASD prevalence vary greatly from population to population and from study to study. Different populations have unique risk factors, especially variations in maternal drinking. The variation found across studies may be due to different research methods used to study the problem. However, researchers generally estimate prevalence of FASD to be at least 1-6 per 1000 births (Abel & Sokol, 1995; Sampson, Streissguth, Bookstein, Little, Clarren, & Dehanne 1997).

In the United States, May and Gossage (2001) found that where the study population was predominately of low social economic status (SES) and African-American
and American-Indian, the estimated FAS rate was 2.29 per 1000. This rate was almost 10 times higher than the rate reported for those study populations that were predominately Caucasian and middle to upper class, .26 per 1000. Several studies have looked at American Indians in very high-risk communities. Low SES generally characterizes these communities and a small but significant proportion of the population frequently binge drink (consuming 5 or more drinks per occasion, on 2 or more days a week) (May & Gossage, 2001). Studies of these communities yield FAS rates that are among the highest in the world with an average rate of 9 per 1000 births. May and Gossage (2001) found that rates of FAS among southwestern Indians in the United States ranged from 0.0 to 26.7 by community, over the period of 1969-1982. Another study in Canada examined every child in an aboriginal village characterized by a concentration of heavy drinkers. The FAS rate reported was 120 cases per 1000 children (Sampson, Streissguth, Bookstein, Little, Clarren, & Dehanne, 1997). In a Native Indian community in British Columbia, Canada, the prevalence rate of FAS/FAE was 190 cases per 1000 children aged up to 18 years (Robinson, Conry, & Conry, 1987). However, the prevalence of FAS is lower in aboriginal communities with highly structured social organizations as opposed to those with more loosely structured ones (Streissguth, 1994). Research has found that among the highly structured groups, the community often ostracized those women who did drink, leading to social isolation and significantly increased drinking patterns. Often, after giving birth to one child with an FASD diagnosis, these women were found to be at significant risk for giving birth to subsequent children with FASD (May, 1991). However, no findings from small and unique communities should be generalized to any other population.
Moreover, the rates referenced above are too high for any population to accept. This lends urgency to the need for research, prevention, and intervention for FASD.

Risk Factors for FASD

The risk factors that have emerged from various studies of FAS, ARBD, and ARND and from studies of alcohol abuse, consistently point to the same issues. There are biological factors that increase the risk for FAS, when associated with heavy drinking, while other factors are associated with the mother’s lifestyle and psychological well-being (May & Gossage, 2001). Many of the risk factors increase risk by leading to heavy prenatal drinking and some are the consequences of alcohol abuse or dependence (Stratton, Howe, & Battaglia, 1996).

The most common and consistent risk factors are related to maternal health. Indices include: being older than 25 years of age when a child is born with FAS; already having three or more children; the use of other drugs, including tobacco and illicit substances; and morbidity or premature mortality from alcohol-related causes (Abel, 1988; Stratton, Howe, & Battaglia, 1996). Abel (1988) added maternal weight, fetal weight, cell development at time of alcohol exposure, overall health of mother, and oxygen deprivation due to maternal liver dysfunction to the risk factors associated with maternal health. Abel (1988) reported that some women could drink heavily during pregnancy and produce a child who is free from FASD while others may drink minimally and produce a child who fits all the diagnostic criteria. The critical factor, or combination of factors, has yet to be determined.

A set of risk factors is related to social economic status (SES). Low SES, social transience, and unemployment, or marginal employment, were all identified as risk factors for FASD (May & Gossage, 2001). Drinking patterns are identified as risks as well. High
risk patterns included early age at onset of regular drinking, frequent binge drinking (consuming 5 or more drinks per occasion on 2 or more days a week), frequent drinking (every day or every weekend), high blood alcohol concentration, and no reduction in drinking during pregnancy (Abel, 1988; May & Gossage, 2001; Stratton et al., 1996). Risk factors associated with psychological well-being included low self-esteem, depression, and sexual dysfunction. The final set of risk factors includes family and social traits; these consist of alcohol misuse in the family, alcohol misuse by the woman’s male partner, tenuous marital status (never married, divorced, or cohabitation), and loss of children to foster or adoptive care (May & Gossage, 2001).

Protective Factors of FASD

In 1996, Streissguth and colleagues examined protective factors that were thought to influence the occurrence of secondary disabilities. Eight factors were found to decrease the likelihood of nearly all the secondary disabilities. These universal protective factors include: 1) living in a stable and nurturing home for over 72% of life, 2) being diagnosed before the age of 6 years, 3) never having experienced violence against oneself, 4) staying in each living situation for an average of more than 2.8 years, 5) experiencing a good quality home from age 8 to 12 years, 6) having applied for and been found eligible for supports from Disability Services, 7) having a diagnosis of FAS (rather than FAE), and 8) having basic needs met for at least 13% of life.

In Streissguth’s sample, the odds of having mental health problems, inappropriate sexual behaviour, and disrupted school experience were reduced primarily by the universal protective factors. The rate of trouble with the law was related to all the universal protective factors; however, incarceration was especially protective when the individual
was living in a stable and nurturing environment and had been diagnosed prior to age 6 (Streissguth et al., 1996). Alcohol and drug problems had one specific protective factor in addition to the universal protective factors: having lived with an alcohol abuser less than the median for the group, the median being 30% of a person’s life (Streissguth et al., 1996). Odds of dependent living were increased fourfold for patients who had an IQ score of 70 or below or a Fetal Alcohol Behaviour Scale (FABS) score below 65 (Streissguth et al., 1996). An extrinsic factor that is protective against dependent living is having a diagnosis before 6 years of age. Odds of problems with employment were increased more than two to fourfold by having an IQ score of 70 or below, and being diagnosed FAS rather than FAE (Streissguth et al., 1996).

As indicated by Streissguth and colleagues (1996), having an early diagnosis is a strong universal protective factor for all secondary disabilities; yet, very few individuals are diagnosed by the age 6. Every effort should be made to diagnose children who may be affected by FAS or FAE. After diagnosis, individuals can apply for services from disability assistance, another strong protective factor (Streissguth et al., 1996).

**FASD in Adulthood**

FASD has been recognized for the past 25 years as a major known cause of developmental disability; yet, it is only in the past 10 years that the lifelong implications of these disabilities began to be acknowledged. Researchers have started to study the difficulties that individuals face in everyday life, including daily living, parenting, and vocational challenges. These challenges manifest from the neurological damage of prenatal alcohol exposure.
Generally, the common characteristics of adults with FASD may include limited impulse control and anger management, minimal understanding of natural consequences, difficulties with financial management, limited ability to think in an abstract manner, problems with generalizing from one situation to another, problems in planning for the future, an ongoing need for immediate gratification, forgetfulness, and a strict need for consistency (Streissguth et al., 1996).

Several researchers have looked at the long-term effects of FASD for individuals (Ladue, Streissguth, & Randels, 1992; Rutman, LaBerge, & Wheway, 2002; Streissguth, 1991; Streissguth, 1993; Streissguth, 1994; Streissguth et al., 1996; Streissguth & Kante, 1997; Streissguth, & O’Malley, 2000; Streissguth et al., 1991). Recently, researchers have conceptualized the disabilities seen in FASD as primary and secondary. Primary disability refers to learning, developmental, and/or physical responses to the environment and other behavioural symptoms that have been associated with the differences in brain structure and function. These behaviours include developmental dysmaturity, sensory integration problems, slow auditory and cognitive processing speed, and difficulties with memory storage, integration, and retrieval, among others (Rutman, LeBerge, & Wheway, 2002). Secondary disability refers to the defensive behaviours that often develop over time as the result of chronic frustration, trauma and/or failure, reflecting a “poor fit” between the needs of the person and his or her environment. These secondary disabilities are not intrinsic to the condition, nor inevitable. They respond to intervention and are found to be preventable. They include anxiety, frustration, anger, shut down, avoidance, aggression, and destructiveness (Rutman, LeBerge, & Wheway, 2002). Discussion of these disabilities will be elaborated in subsequent sections.
Primary Characteristics in Adulthood

Researchers have recently begun to study the relationship between prenatal exposure to alcohol and deficits in executive functioning (EF) in adulthood. EF refers to cognitive functions involved with planning and guiding behaviour in order to achieve a goal in an efficient manner (Kodituwakku, Kalberg, & May, 2001). EF can also be seen as deliberate or effortful actions that involve various abilities, such as holding or manipulating information “in the head” and focusing on one task at a time (Kodituwakku, Kalberg, & May, 2001). Executive functioning can be divided into two categories: cognition-related actions (problem-solving) and emotion-related actions (positive and negative reinforcements). Researchers have found that different brain regions are responsible for controlling cognition-related executive functioning and emotion-related executive functioning. For example, Kodituwakku and colleagues (2001) reported that individuals prenatally exposed to alcohol with damage in the orbitofrontal cortex performed poorly on an emotion-related decision making task but completed the task which assesses cognition-related executive functioning with ease. Although it is difficult to determine a threshold of alcohol consumption for such adverse effects of brain damage, Jacobson and Jacobson (1994) obtained evidence that seven standard drinks per week may be the threshold for most sensitive behavioural measures; however, this threshold does not apply to all women and babies. Although moderate alcohol moderate exposure (i.e., 7.0 to 13.9 drinks per week) may produce impairments of executive functioning, no relationship has been found between the number of abnormal physical features associated with heavy prenatal alcohol exposure and the degree of executive functioning deficits in affected people. In other words, people with full-blown Fetal Alcohol Syndrome (FAS), the most severe
consequence of prenatal alcohol exposure, and people exposed but without FAS may both exhibit executive functioning deficits to the same degree (Connor & Streissguth 1996; Kodituwakku et al., 2001).

Problems that individuals face when there is brain damage include difficulty in learning new information; this difficulty is due partly to the inability to employ effective learning strategies and to impulsivity (Kodituwakku et al., 2001). Prenatal alcohol exposure affects many regions of the brain and leads to a wide variety of disturbances. Problems tend to occur in a number of important areas, including attention, intelligence, memory, motor coordination, complex problem solving, and abstract thinking. In general, people with FAS and ARND often have a hard time focusing their attention (Brown et al., 1991). In particular, attentional disturbances were prominent in adolescents; these adolescents made impulsive errors on vigilance tasks requiring focusing and sustaining attention (Streissguth et al., 1996).

Connor and Streissguth (1996) reported that people with FAS have difficulty with cognitive estimation, a category of tasks that requires the subject to estimate sizes, weights, amounts, and lengths of items when they may not know the exact answer (e.g., “What is the height of the tallest tree in the world?”). People with FAS/ARND tend to give more extreme answers to many of these types of questions than would be expected. Kerns, Mateer, and Streissguth (1997) found that adolescents and adults with FAS and FAE had significant difficulty performing tasks involving the calculation and estimation of numerical concepts, although they could read and write numbers. This type of deficiency makes independent living difficult, especially in regard to managing finances.
Researchers have observed that people's performance on cognition-based executive functioning tasks is similar to their performance on a range of fluid intelligence tests measuring a person's ability to solve new problems quickly and accurately. These tasks require the ability to hold information in working memory. Preliminary evidence suggests that alcohol-exposed adults have more difficulty with fluid intelligence tests than with crystallized intelligence tests (Kodituwakku et al., 2001).

Standardized IQ tests reveal a wide variability in presentation among adults afflicted with FASD (LaDue, Streissguth, & Randels, 1992; Stratton, Howe, & Battaglia, 1996; Streissguth et al., 1991). In general, IQ scores for this population have been found to range from severely disabled to normal range with an average IQ of about 70 (LaDue, Streissguth, & Randels, 1992). A person with an IQ of 70 or below is considered mentally handicapped (DSM-IV). Intellectual functioning, as measured by standardized IQ tests, is often below average in children and adolescents with FAS or FAE (Kodituwakku et al., 2001). Clark, Lutke, Minnes, and Ouellette-Kuntz. (2004) found that, although the average IQ of subjects with FASD was 76, there was a range of 45 to 120. Approximately one third of the clients studied had an IQ score below 70 (Clark et al., 2004), yet the majority of the clients required a moderate to high level of care. Previous studies that looked at both the IQ and adaptive skills of individuals with FASD noted a gap between IQ and adaptive skills (Streissguth et al., 1996, Streissguth et al., 1991). Although, individuals prenatally exposed to alcohol may have an IQ in the normal range, their adaptive functioning is often impaired and they may have significant trouble living independently in adulthood. The literature states that it is important to assess adaptive behaviour of a suspected individual because IQ scores do not correlate well with adaptive behaviour nor do they provide an indication of
the individual’s success at living independently (Astley & Clarren, 2000). Another caution in administering and interpreting IQ tests is that one must be careful not to interpret a higher performance IQ as a definite indication of central nervous system (CNS) dysfunction, because there is data to suggest that performance IQ is often higher than verbal IQ in aboriginal people (Astley & Clarren, 2000).

Researchers found that performance IQ (PIQ = 84 for FAS, and PIQ = 93 for FAE) was higher than verbal IQ (VIQ = 79 for FAS and VIQ = 88 for FAE) among those with FAS and FAE. This discrepancy suggests CNS dysfunction related to memory problems and abstracting abilities (LaDue, Streissguth, & Randels, 1992). These authors noted that memory problems were observed in 73% of individuals with FAS/FAE. These abstracting and memory deficits are thought to affect not only academic functioning but also functioning in daily life. Memory impairment may cause someone to have difficulty learning from experience, while difficulty with abstraction may create problems understanding consequences. Streissguth and colleagues (1996) found that 68% of FAS/FAE participants in three age groups (children, adolescents, and adults) had received services for learning problems in school. These results suggest that IQ alone is not a sufficient criterion for determining the need for support services among persons with FASD.

Individuals with FASD often have difficulty with memory. Kerns and colleagues (1997) found that patients with FAS had difficulty recalling a list of words even after hearing the list five times. Many added words that were not on the original list. Conner, Sampson, Bookstein, Barr, and Streissguth (2000) studied memory by comparing adults with FASD to adults with no history of prenatal alcohol exposure. In relation to the
comparison group, the FASD group exhibited substantial deficits in auditory and visual attention. In addition, when asked to remember number sequences and reverse the sequence in their head, a task requiring concentration and short term memory, adults with FASD performed in the low-average range. Other memory problems that are evident in FASD adults are slow learning, low levels of retention (i.e., they may demonstrate impairment on tasks that require them to retain, manipulate and manage more complex amounts of information), and inconsistent memory (LaDue et al., 1992). It appears from the literature that memory and processing skills and the ability required to establish clear, well-organized learning might be inadequate in adults with FASD. The difficulties in memory functioning that have been observed suggest that people with FAS/ARND may forget their obligations at school or work, or forget medical appointments. Because of memory problems, affected individuals often require reminders of their appointments or other environmental accommodations such as calendars and alarm clocks.

The literature on FASD has revealed that people prenatally exposed to alcohol display marked behavioural problems, particularly social deficits (Connor & Streissguth, 1996). In fact, researchers have identified that social and adaptive functioning is the major concern reported by caretakers and clinical observers of adults with FASD (LaDue, Streissguth, Randels, 1992). LaDue and colleagues (1992) examined adaptive functioning using the Vineland Adaptive Behaviour Scales in a sample of 92 adolescents and adults with FASD. These researchers found a very low overall level of adaptive functioning, much below the person's chronological age. Individuals often appeared very alert and verbal; however, on average, written and verbal communication skills and expressive and receptive language were at the level of an 8-year-old, and scores on the daily living skills
subscales were at the level of a 9-year-old. This latter scale measures more repetitive and concrete skills such as hygiene, money use, time, and job skills. Individuals performed worst in the socialization domain, with the average score at the level of a 7-year-old. This scale measures skills that are more abstract and subtle, such as interpersonal skills and ability to follow social rules and conventions. No differences were found on adaptive behaviours between those with FAS and FAE. Clearly, poor adaptive behaviour is characteristic of this population, and, as some researchers have suggested, may be their most handicapping disability (Streissguth, LaDue, & Randels, 1998).

**Secondary Characteristics in Adulthood**

Secondary disabilities are behaviours that are a reaction to the primary disabilities associated with prenatal alcohol exposure. Streissguth and colleagues (1996) analyzed primary and secondary disabilities among 473 people with FASD (aged 6 to 51 years, median age of 14.2 years). Of this sample, 87 participants were over the age of 18 years. In order to study secondary disabilities, researchers used the Life History Interview (LHI). This interview was developed for this particular study to evaluate patients of any age and any degree of disability. The interview was administered to a caretaker or informant about the affected person and covered ten major domains of possible long-term functional consequences of prenatal exposure to alcohol. These domains included: (a) household and family environment, (b) independent living and financial management, (c) education, (d) employment, (e) physical abuse, sexual abuse, and domestic violence, (f) physical, social, and sexual development, (g) behaviour management and mental health issues, (h) alcohol and drug use, (i) legal status and criminal justice involvement, and (j) companionship and parenting.
Streissguth and colleagues (1996) identified six main categories of secondary disabilities. The first category, mental health problems, was experienced by 90% of the individuals. The second category, disrupted school experience, defined as having been suspended or expelled from school or having dropped out of school, was experienced by over 60% of the individuals 12 and older. The third category, trouble with the law, defined as ever having been in trouble with authorities, charged, or convicted of a crime, was experienced by 60% of the individuals 12 years or older. In more recent research, Clark and colleagues (2004) found that, for affected individuals, living with a caregiver was associated with a decreased likelihood of getting into trouble with the law. The fourth category, confinement, including in-patient treatment for mental health problems or alcohol/drug problems, or ever having been incarcerated for a crime, was experienced by about 50% of the patients 12 years and older. The last two categories are inappropriate sexual behaviour and alcohol and drug problems. Inappropriate sexual behaviour was noted for approximately 50% of the patients 12 years and older and 30% of the sample had received treatment for drug and alcohol problems (Streissguth et al., 1996). The researchers also made an effort to determine how many patients over the age of 21 became self-sufficient; 80% of the sample was in dependent living situations and 80% had problems with employment. Only 7 of the 90 adults in the study lived independently and without employment problems (Streissguth et al., 1996). Gender differences were found in this study as well; males had higher rates of disrupted school experiences, trouble with the law, and confinement than females. Otherwise, rates of secondary disabilities were equal across the sexes (Streissguth et al., 1996).
Violence against individuals with FAS/FAE tended to occur at an alarming rate; 72% had experienced physical or sexual abuse or domestic violence. Being a victim of violence was a strong risk factor for inappropriate sexual behaviour; being a victim of violence increased the odds fourfold (Streissguth et al., 1996).

Clark and colleagues (2004) examined the effects of secondary disabilities among adults with FAS in British Columbia. These researchers administered the Functional Assessment, a tool used by the British Columbia Ministry for Children and Family Development to assess level of care needed by an individual, by measuring for the level of adaptive functioning among clients. Six main areas of functioning were evaluated: personal care, daily living skills, community access, social skills, maladaptive behaviour, and health and physical care demands. Participants with co-morbid diagnoses or involvement with justice departments were more likely than other participants to have supports such as disability benefits, supported living services, and assisted employment services. These researchers found that caregivers described 92% of the clients as being vulnerable to manipulation, 87% having experienced some form of violence, and 77% having experienced either physical or sexual abuse (Clark et al., 2004).

In terms of independence and employment, adults with FAS/FAE face many challenges. In Streissguth and O'Malley’s (2000) study of secondary disabilities, they found that 80% of the study subjects were still living dependently and about 80% had major problems with employment. Only 7 of the 90 adults in the study sample lived independently and did not have major employment problems. In a similar study of long-term outcomes for FAS, Streissguth and colleagues (1994) concluded that only 6 of the 52 subjects in the study sample were able to live independently with regard to income,
occupation, and lifestyle. Although 56% were not able to attend regular schools and none had graduated from high school, many were able to work in simple occupations that apparently kept them busy and out of trouble (Streissguth et al., 1994).

**Mental Health**

As indicated by Streissguth and colleagues (1994), the most prominent disability among FASD affected adults was mental health problems, defined as ever having gone to a psychotherapist or counsellor for a mental health problem. This was experienced by over 90% of the full sample of Streissguth’s (1991) study on secondary disabilities. Similar to the earlier findings by Streissguth and colleagues (1996), Clark and colleagues (2004) found that the most common secondary disabilities experienced were mental health problems (92%) and disruptive school experiences (61%).

The most common mental health diagnosis was attention deficit disorder/attention deficit hyperactivity disorder (65%), followed by depression (47%), and panic disorder (21%). Streissguth and O’Malley (2000) produced a study of 61 adolescents and adults with FASD; they concluded that Fetal Alcohol Syndrome is not just a childhood disorder. In fact, there is a predictable, long-term progression into adulthood of the disorder, in which maladaptive behaviours present the greatest challenge to treatment. Streissguth and O’Malley (2000) found that mental health problems constituted the most severe manifestations of FASD in adulthood. These researchers’ findings identified that 90% of FASD individuals seek assistance from mental health professionals; 50% had been in a confinement setting at some point in their lives, either a psychiatric hospital, a jail, or prison, or an inpatient alcohol/drug treatment program; and 40% had threatened suicide (Streissguth & O’Malley, 2000). These persisting problems often prevented these adults...
from effectively using their intellectual potential and even their manual skills. They could not focus on their work or their work environments because of their immaturity, considerable instability, and refusal to cooperate. Restlessness and hyperactivity concealed their lack of assurance and initiative as well as their need for assistance and protection (Streissguth & O’Malley, 2000). Although these adults were often euphoric and excited, they were also fearful, anxious, and depressed. Some were jokesters and comics; others were irritable and aggressive (Streissguth & O’Malley, 2000).

Transgenerational

One of the most troublesome findings from Streissguth and O’Malley’s (2000) study was that, of the 415 individuals in the study, 30 women with FAS or FAE had given birth to a child. Of these 57% no longer had custody of their child, 40% were drinking during pregnancy, and several had children diagnosed with or suspected of having FAS or FAE. None of the women who gave birth had an IQ score below 70, but they did have high rates of secondary disabilities. This alarming finding regarding the transgenerational transmission of fetal alcohol brain damage sheds new light on the often noted difficulty with working with high risk mothers with alcohol and drug problems.

Parenting with FASD

Only a handful of researchers are examining the challenges parents with FASD face in raising children. In fact, there is a lack of information about deciding which parents are affected with FASD and how they function in their role as parents and what impact parenting has on them. In combination with the lack of adaptive and cognitive skills these parents endure, they frequently face additional problems such as poverty, lack of vocational skills, lack of knowledge about community services and an experience of poor parenting.
from their youth. Researchers have begun to examine the strengths and challenges of parenting with FASD.

Rutman and Copeland (1996) asked parents with FASD about their challenges with parenting. These parents reported that the two most challenging barriers were learning and independent living. The specific parenting challenges were a lack of financial resources required to care for a child. Young mothers also spoke about other people’s lack of confidence in their ability to be a good parent; this represented a significant obstacle for the mothers in their efforts to develop skills and access support. These parents reported difficulties in their undertaking of day-to-day planning and decision-making in areas such as meal planning and preparation. Moreover, parents acknowledged that the parenting challenges associated with FAS/FAE multiplied as the child grew older and his or her needs became more involved and required increasingly complex decision-making skills on the part of the parent (Rutman & Copeland, 1996).

The parents from the study by Rutman and Copeland (1996) identified low-levels of education and lack of employment as a barrier. In their study about secondary disabilities, Streissguth and colleagues (1996) also identified low levels of education and/or school difficulties as major problems in the FASD population. These on-going school difficulties from elementary to secondary school leave long-term hurdles for parents. Lack of accomplishment in education may create low self-esteem, lack of knowledge, isolation, and poor socialization skills, all of which are important for parenting. Furthermore, parents want and need time on their own, away from their child, to regain their sense of identity and independence. These findings highlight the importance of further research into the needs of parents with FASD, to best support them in their roles.
These same parents discussed their achievements in parenting. Young mothers were found to be especially proud of their self-care during pregnancy and of their delivery of a healthy, robust child (Rutman & Copeland 1996). Participants in Rutman and Copeland’s (1996) study also highlighted the care they gave their children during the first year: they breastfed and provided comfort to their babies, and were able to attend to their children’s needs for food, cleanliness, security and love.

*Diagnosis of FASD*

The core triad of impairments for a diagnosis of FASD include prenatal growth deficiency, facial anomalies, and central nervous system dysfunction (Clarren, Alvord, Sumi, Streissguth, & Smith, 1978). The core triad of impairments were developed for children affected by FASD and not necessarily for adults. Few people are diagnosed with FASD in their adult years because current diagnostic criteria are not valid for adults. At this time, diagnosis is difficult due to the limitations in knowledge and availability of information about adults affected by FASD. These limitations create special challenges in all aspects of the diagnosis. Researchers have reported that FASD may go unrecognized, misdiagnosed, and underreported in adults.

*Current Diagnostic Guidelines*

Currently, there are two major sets of diagnostic criteria used to assess FASD: the criteria set out by the Institute of Medicine (IOM) in 1996 and the 4-Digit Diagnostic Code published by Clarren and Astley in 2000. In 2005, researchers developed Canadian guidelines for FASD diagnosis; these include both the Institute of Medicine criteria and the 4-Digit Diagnostic Code, with modifications. These three diagnostic tools will be discussed briefly in subsequent sections.
Institute of Medicine (IOM). The IOM requires “evidence of a complex pattern of behaviour or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment” (Stratton, Howe, & Battaglia, 1996). The IOM criteria has five categories for diagnosing FASD:

- Category 1 – FAS with confirmed maternal alcohol exposure
- Category 2 – FAS without confirmed maternal alcohol exposure
- Category 3 – Partial FAS with confirmed maternal alcohol exposure
- Category 4 – Alcohol-related birth defects with confirmed maternal alcohol exposure and the presence of consistent physical anomalies
- Category 5 – Alcohol-related neurodevelopmental disorder with confirmed maternal alcohol exposure and neurodevelopmental abnormalities and or behavioural or cognitive deficits (Institute of Medicine, 1996).

Please refer to Appendix C for a detailed description from the IOM diagnostic criteria.

4-Digit Diagnostic Code. Astley and Clarren (2000) created a 4-Digit Diagnostic Code using data from the Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network of clinics. The system uses quantitative, objective measurement scales and specific case definitions (Chudley et al., 2005). The 4-Digit Diagnostic Code utilizes the expression of the key diagnostic features. The diagnostic criteria reflect the magnitude of expression of key diagnostic features. The degree of expression of each feature is ranked.
independently using a four-point likert scale to provide a numerical reference to the absence or presence of certain FASD characteristics, with 1 representing the complete absence and 4 representing a classic pattern of the characteristic (Astley & Clarren, 2000). The evaluation of FASD is based on the levels of certainty, in the judgement of the clinician, that the individual's cognitive and behavioural problems reflect brain damage. The determination is based on objective evidence of “substantial deficiencies or discrepancies across multiple areas of brain performance” (Astley & Clarren, 2000). Please refer to Appendix D for a detailed description of the diagnostic criteria. Although the approaches are different, the underlying fundamental criteria of the IOM and the 4-Digit Diagnostic Code are similar. Some practitioners are integrating the diagnostic tools reflected by the 4-Digit Diagnostic Code with the diagnostic categories and language recommended by the IOM committee (Chudley et al., 2005).

Canadian diagnosis guidelines. More recently, in 2005, Chudley and colleagues produced Canadian guidelines for diagnosing FASD, based on the results of more than 10 face-to-face consultations with Canadian and American experts in the diagnosis of FAS and its related disabilities. The researchers recommend, based on the complexity of the disabilities associated with prenatal alcohol exposure, that a comprehensive, multidisciplinary assessment is necessary. The team for diagnosis would ideally consist of a coordinator for case management, a physician specifically trained in FASD diagnosis, a psychologist, an occupational therapist, and a speech-language pathologist. A comprehensive team for FASD assessment would have the ability to share important information about the individual’s unique needs and allow interventions to be tailored to individual strengths and challenges. The post-diagnostic report should state the basis for
the diagnosis, including the history of alcohol use, the physical criteria, and the psychological data that support the diagnosis (Chudley et al., 2005). Chudley and colleagues (2005) emphasized the importance of community and family involvement with the diagnostic process. In particular, the diagnostic process should be sensitive to the family's needs, and the family should be made aware of the potential psychosocial consequences of a diagnosis of FASD.

The Canadian guidelines include 6 areas related to the diagnostic process: 1) screening and referral; 2) the physical examination and differential diagnosis; 3) neurobehavioral assessment; 4) treatment and follow up; 5) maternal alcohol history in pregnancy; and 6) diagnostic criteria for FAS, partial FAS, and alcohol-related neurodevelopmental disorder. Each of the 6 areas outlines, in detail, the latest scientific knowledge and best practice recommendations to accurately diagnose FASD. The guidelines adapted the method of the 4-Digit Diagnostic Code with regard to identifying domains and severity of impairment of brain damage. However, the researchers reported that a single feature, such as microcephaly, is not a sufficient indicator of brain damage for the purposes of an FAS diagnosis because it may reflect genetic or ethnic differences not reflected in currently available norms (Chudley et al., 2005). Furthermore, the diagnostic profile should be dynamic and may change over time; thus individuals affected or suspected to be affected may require several assessments over time. Following an assessment, services should not be based on the diagnosis itself, but rather on the profile of brain function-dysfunction (Chudley et al., 2005).
Diagnosis of FASD in Adulthood

Chudley and colleagues (2005) developed Canadian guidelines for diagnosis of FASD; however, these researchers clearly state that diagnosis of adults creates special challenges in all aspects of the diagnosis. The features of FASD are complex and multifaceted, originating with organic brain damage caused by alcohol, but interacting with genetic and other influences. Over the lifespan of the affected person, these features may be exacerbated or mitigated by environmental experiences (Chudley et al., 2005). The physical features of individuals who were exposed to alcohol prenatally vary considerably. In adulthood, individuals’ facial features tend to normalize with age, making a diagnosis of FASD troublesome based on the current criteria (i.e., short palpebral fissures, elongated and indistinct philtrum, thin upper lip) (Stratton, Howe, & Battaglia, 1996). However, these features only occur as a result of alcohol exposure at a specific time, early in pregnancy. Jacobson and Jacobson (1994) identified that damage to facial features can occur between 14 and 28 days after conception. In most cases, estimated to be between 16-35% of births with prenatal exposure to alcohol, there are no observable physical characteristics of that exposure (Jones & Smith, 1973). Due to the low estimates of damage to facial features in FASD affected individuals, this population has been referred to as having an “invisible handicapping condition” because presenting behavioural characteristics may be the only symptoms of the underlying neurological disability (Clarren & Smith, 1978). Adults in whom damage to facial features can be seen stem from head circumference that is smaller than normal, a broad face with wider than normal space between the eyes, ears that are a little bit lower on the head then usual, a thin upper lip, short nose, and eyes with epicanthal folds (Mattson & Riley, 1995).
As stated previously, diagnoses of FASD in adulthood are particularly difficult for several reasons. It is clear that identification by facial features is problematic in adulthood (Streissguth, Aase, Clarren, Randels, Ladue, & Smith, 1991) and that identifying by facial features alone would exclude many of the individuals with FAE (Conner & Streissguth, 1996). Also, the facial features that are common in children with FASD quite often disappear by the time the children become adults. Streissguth (1991) reported that facial appearance begins to normalize with age as continued slow growth of face, chin, nose (height of nasal bridge and length of nose), and modeling of the philtrum and upper lip through adolescence compensates for underdevelopment of the mid-face. Conner and Streissguth (1996) recommend that it is not accurate to view FAE always as a milder form of FAS or that FAE deserves less recognition or treatment because the social, behavioural, and neurological deficits are just as devastating, and in some cases, are more devastating than those seen with FAS.

The cumulative environmental influences may distort the evaluation of brain function, and this, in turn, interferes with the diagnosis of FASD for adults (Chudley et al., 2005). In addition to the brain damage caused by prenatal alcohol exposure, traumatic head injury, alcohol and drug abuse, and mental health problems may be present and may affect neurological and behavioural presentation in adulthood.

Tests that are currently available are not sensitive to the real life issues of the FASD population. The clinician should not rely solely on the self-report of the individual who is alcohol-affected, and the history and abilities of the individual need to be verified by a reliable source (Chudley et al., 2005). Furthermore, Chudley and colleagues (2005) have recommended that a multidisciplinary approach is essential for an accurate and
comprehensive diagnosis. Not only will a diagnosis assist in explaining why FASD affected adults are different from their peers, but also in identifying effective interventions to avoid the secondary disabilities often associated with FASD. In other words, it is imperative to link diagnosis with available resources and services.

**Current Assessment Practices**

Guidelines are set forth in the Standards for Educational and Psychological Testing for determining who can administer and interpret tests. Some tests take considerable skill to administer and interpret and are restricted to individuals with at least a master’s degree in psychology and specific training in the particular test (level C tests). Other tests are less complex and only require completion of a university course in psychometric assessment and some supervised experience in administering, scoring, and interpreting tests (level B tests). Finally, some tests are simple to administer and interpret and can be used by anyone familiar with the test manual (level A tests) (Guidelines for Educational and Psychological Testing, 1998). Due to the above-mentioned guidelines, diagnosis is difficult in Northern British Columbia because of the lack of professionals able to administer and interpret the appropriate tests needed to diagnose FASD in adulthood. This underscores the importance of establishing a screening tool that can capture these unique differences and guide appropriate interventions and further assessments.

A review of literature has shown that there is a gap in FASD research for adults. In Canada, no standardized screening tools have been developed to help identify individuals who may have FASD (Chudley et al., 2005). Currently, no validated screening tool for FASD is available, with demonstrated reliability to detect the neurobehavioral effects of prenatal alcohol exposure in adults. Chudley and colleagues (2005) reported that there is a
need for the development and validation of screening tools that are specific and sensitive to prenatal alcohol exposure. Furthermore, these tools should be adaptable for use in various contexts, be culturally appropriate and lead to accurate referrals for diagnosis and assessment. Streissguth (1994) suggested that each community should have a referral network, as well as screening programs, to aid in the identification process. Therefore, research is needed to develop sensitive and effective screening tools that are adaptable to different contexts.

_Cognitive Assessment_

The assessment of intellectual and cognitive functioning has been an important professional activity for clinical psychologists for almost a century. A great deal of effort has gone into ensuring that tests are fair, that adequate normative data are gathered, and that assessments are both reliable and valid (Hunsley & Lee, 2006). Intelligence tests are used to measure the cognitive ability of an individual through establishing the individual’s standing among his or her peers. Intelligence tests do not tap the full range of abilities; instead, they focus on those abilities that are related to academic performance only and are not designed to measure social or emotional domains. There are broad definitions of intelligence, such as the ability to learn or to adapt to the environment, and narrow definitions, such as the ability to engage in abstract thinking (Hunsley & Lee, 2006). Wechsler (1939) defined intelligence as a person’s global capacity to act purposefully, to think in a rational manner, and to deal effectively with his or her environment. Wechsler’s definition of intelligence has continued to influence the way clinical psychologists evaluate intelligence.
The most widely used intelligence tests are the Wechsler Intelligence Scales and the Stanford-Binet Intelligence Scale. The Wechsler Intelligence Scales have been in existence since 1939, when Wechsler first published the Wechsler-Bellevue Scale. The Wechsler Intelligence Scales are considered to be the gold standard of cognitive assessment devices for the clinician (Kaufman & Lichtenberger, 1999). The Wechsler Intelligence scales have sound construction and outstanding psychometric properties. There are four Wechsler Intelligence Scales: the Wechsler Adult Intelligence Scale-Third Edition, designed for the age range of 16-89 years, the Wechsler Intelligence Scale for Children-Fourth Edition, designed for the 6-16 age range, the Wechsler Preschool and Primary Scale of Intelligence-third Edition, designed for the age range from 2 years 6 months to 7 years 3 months, and the Wechsler Abbreviated Scale of Intelligence, designed for 6 years to 89 years (Hunsley & Lee, 2006; Kaufman & Lichtenberger, 1999). All four tests measure the same attributes: verbal comprehension, perceptual organization, working memory, processing speed, and general language (Kaufman & Lichtenberger, 1999).

The Stanford-Binet Intelligence Scale was developed in 1905 and is considered to be the first intelligence test (Couzens, Cuskelly, & Jobling, 2004). The Stanford-Binet Intelligence Scale is now in its fifth edition. It is designed to assess intelligence in individuals from to 2 to 85 years of age. The Stanford-Binet Intelligence Scale was originally developed to help place children in appropriate educational settings (Couzens, Cuskelly, & Jobling, 2004). It can help determine the level of intellectual and cognitive functioning in preschoolers, children, adolescents, and adults, and assist in the diagnosis of a learning disability, developmental delay, mental retardation, or giftedness (Couzens, Cuskelly, & Jobling, 2004). It is used to provide educational planning and placement,
neuropsychological assessment, and research. The test items of the Stanford-Binet scale are based on the ability level, rather than chronological age, of the individual being tested (Hunsley & Lee, 2006). The scale permits individuals to be assessed on the same instrument across time, making age-related comparison possible. The Stanford-Binet was designed to reflect a three-level hierarchical model of the structure of cognitive abilities. The test consists of 15 subtests, which are grouped into the four area scores. Not all subtests are administered to each age group; but seven subtests are administered to all ages. These subtests are: Vocabulary, Word Knowledge, Comprehension, Pattern Analysis, Quantitative, Bead Memory, and Memory for Sentences (Couzens, Cuskelly, & Jobling, 2004).

Intelligence testing is a powerful indicator of the integrity of the individual’s global cognitive abilities. The profile of the intellectual strengths and weaknesses provides information about the individual’s needs. Adults with FASD demonstrate limited cognitive abilities that may be responsible for their functioning at lower levels. However, most adults with FASD, even those with an IQ in the normal range, show specific cognitive deficits (Kerns et al., 1997). Adults affected by FASD may demonstrate higher scores in particular areas of the intelligence test and lower scores in other areas. Therefore, when intelligence tests are used with other measures, the clinician is able to obtain invaluable information about the individual’s learning style, resulting in appropriate recommendations for educational intervention, modification, or accommodation.

Adaptive Functioning

Adaptive behaviour comprises independent functioning levels (i.e., feeding, cooking, dressing, toileting, hygiene, travelling, health, safety, money management,
shopping, etc.), social functioning (i.e., communication skills, social interaction skills, sexual behaviour, childcare), and school or vocational functioning (i.e., reliability, performance, safety) (Sparrow, Bella, & Cicchetti, 1984). A person learns these skills in the process of adapting to his/her environment. Adaptive behaviours are developmental; it is possible to describe a person’s adaptive behaviour as an age-equivalent score. An average 6-year-old, for example, would be expected to have adaptive behaviour similar to that of other 6-year-olds.

Sparrow, Bella, and Chiccetti (1984) outlined three important principles, which they considered inherent to adaptive functioning. First, adaptive behaviour is age related, in that adaptive behaviour increases and becomes more complex as an individual grows older. Second, adaptive behaviour is defined by the expectations of other people; moreover, the adequacies of an individual’s adaptive behaviour are judged by those who live, work and interact with the individual. Finally, adaptive behaviour is defined by typical performance of daily activities, not ability. These principles do not appear entirely relevant in the assessment of adaptive functioning of people who have FASD. Streissguth and colleagues (1996) identified dysmaturity as one of the primary disabilities of FASD individuals; generally, FASD affected individuals’ developmental age is lower than their chronological age. For example, 18-year-olds with FASD could show emotional/social functioning that is similar to an 8-year-old without FASD.

Adaptive Behaviour Scales

Individuals with FASD should always have an adaptive behaviour assessment as part of any comprehensive assessment of abilities (Rutman, LaBerge, & Wheway, 2002). Scales of adaptive behaviour measure the person’s functional levels in various life skills.
Scales are an important way of determining how well an adult is adjusting to, or coping with, their living situation and environment. Average adaptive functioning in adulthood is somewhere between age 7 and 12 years for individuals with FASD (Rutman, LaBerge, & Wheway, 2002). Adaptive behaviour tests are primarily combinations of third-party reports of a person’s abilities and interactive tests with the individual. Social and adaptive skills are considered the most important for assessment (Streissguth, Ladue, & Randels, 1998), but available standardized instruments do not adequately tap the unusual adaptive problems found in FASD.

Tests of adaptive functioning determine whether the person has a developmental delay, and whether the delay is global or specific. This in turn is useful for program planning and for establishing a baseline for intervention. In adults, tests of adaptive behaviour are also useful in assessing the person’s potential for living independently and/or the degree and nature of supports required for this to happen. There are dozens of tests of adaptive functioning; however, based on reliability, validity, and comprehensiveness, the best tests currently available are the Vineland Adaptive Behaviour Scales (VABS), published in 1984, and the Scales of Independent Behaviour-Revised (SIB-R), published in 1996.

*Vineland Adaptive Behaviour Scales (VABS).* The Vineland Adaptive Behaviour Scales have been normed for individuals aged 3 through 18 years, 11 months. The VABS has three versions: the Classroom Edition, the Survey Form, and the Expanded Form. Each version measures adaptive behaviour in four domains: daily living skills, socialization, motor skills, and maladaptive behaviour (Sparrow, Bella, & Cicchetti, 1984). The Daily Living Skills Domain has 92 items assessing skills in the area of personal, domestic, or
community skills. The Socialization Domain has 66 items assessing interpersonal relationships, play and leisure, and coping skills. The Motor Skills Domain has 36 items assessing fine motor and gross motor skills. The Maladaptive Behaviour domain has 36 items, assessing minor and major maladaptive behaviours. The VABS have been seen as a stronger test for developmental assessments, assessments of severe and profound retardation, assessments of older/higher functioning individuals, and for making explicit distinctions between receptive and expressive language and gross and fine motor skills (Rutman, LaBerge, & Wheway, 2002). A trained interviewer administers either form to a parent or caregiver of an individual from birth to 18 years 11 months or a low-functioning adult. This test takes approximately 60-90 minutes to complete, and must be administered by a psychologist, social worker, or other professional with a graduate degree and who has training in interview techniques, as it is a Level B test (Sparrow, Bella, & Ciccehetti, 1984). The VABS data can provide reliable and valid estimates of an individual’s adaptive behaviours in comparison with a national (American) normative group of 3,000 individuals (Sparrow, Bella, & Ciccehetti, 1984).

Scales of Independent Behaviour-Revised (SIB-R). The Scales of Independent Behaviour- Revised (SIB-R) is a comprehensive adaptive functioning measure, similar to the VABS. The SIB-R is designed for assessing individuals from infancy to 80+ years (Bruininks, Woodcock, Weatherman, & Hill, 1996). The SIB-R assesses 13 areas of adaptive behaviour: Gross Motor Skills, Fine Motor Skills, Social Interaction, Language Expression, Eating and Meal Preparation, Toileting, Dressing, Personal Self-Care, Domestic Skills, Time and Punctuality, Money and Value, Work Skills, and Home Community Orientation. It contains an excellent behaviour problem scale in addition to its
adaptive behaviour assessment, and provides a unique score, which reflects overall independence based on adaptive and maladaptive behaviour combined. Its norms are based on the performance of a representative (American) sample of 2,182 individuals. This semi-structured interview of an informant familiar with the individual’s daily activities takes about 45-90 minutes to administer. The SIB-R is superior to the VABS in the assessment of vocational skills, money/property management skills, and higher-level motor skills. This test can be used to assess adults; however, it is also a Level B test.

Limitations for both the VABS and the SIB-R include the need for a considerable amount of time as well as a specific level of expertise in administering, scoring, and interpreting. A master’s level education is needed to administer these tests. The VABS is not designed to assess functioning in adults, and neither measure is specifically designed for use with the FASD population but rather for a more general population with normal or impaired adaptive functioning. Researchers in the field of FASD reported that observation and interview, school reports, and previous assessments, such as the Vineland Adaptive Behaviour Scales, have been found to be inadequate for higher ages (Chudley et al., 2005)

**Screening Tools**

There is no gold standard when developing or evaluating screening tools nor are screening tools regulated by scholarly societies or governmental agencies. Thus, examiners need to be vigilant of a given tool’s particular characteristics and the purpose for developing or administering screening tools. Despite the lack of regulatory procedures, researchers have outlined guidelines for developing and/or administering screening tools.

Screening tools are generally used to detect the presence or absence of some attribute in people. Streiner (2003) defined screening tools as a way of determining whether
individuals have the attribute in question by testing a large group of asymptomatic people. Groups who are assessed with screening tools can range from everyone in the population to more individualized, case finding approach among people at high risk. Screening tools should be used for improving the rate of identification. Screening tools, used to identify individuals for future diagnosis and assessment, should not be equated with diagnosis or assessment. Screening has three main purposes: to facilitate referral to a diagnostic clinic, to highlight the need for referral, and to support the individual who is suspected of FASD. Specifically, the purpose of screening individuals at risk for the effects of prenatal alcohol exposure is to determine whether a pattern of learning and behavioural problems is present, possibly relating to prenatal alcohol exposure (Chudley et al., 2005). Especially when completing screening tools for FASD, the person administering the tool should take into account the individual’s level of stamina and environmental disturbances, so to get the best assessment possible.

Screening tools can be very useful in many settings and for many individuals. Screening can take place in many settings; these include the education system, the mental health system, the judicial system, or the social services system (Chudley et al., 2005). Screening can take place through different mediums such as, the telephone, face-to-face interview, internet, the mail, and manually while awaiting consultation (Rydz, Shevell, Majnemer, & Oskoui, 2005). An ideal screening tool should be quick to administer and easy to score (Shulman, 2000), well tolerated and accepted by individuals, and relatively independent of culture, language, and education (Kalbe et al, 2005). Furthermore, Rydz and colleagues (2005) reported that screening tools should be economically viable, reliable, and valid, as well as highly sensitive and specific. Screening tools should also have good
inter-rater and test-retest reliability as well as concurrent validity and predictive validity (Kalbe et al., 2004; Shulman, 2000). Properties of screening tools are presented in FASD research; however the research demonstrates that screening tools are not widely used for FASD (Kalbe et al., 2004).

A study by Rydz and colleagues (2005) showed that approximately 20% of primary care clinicians used a standardized tool when a psychosocial problem was recognized, whereas up to 50% never used a standardized instrument. The infrequent use of screening tools has also been documented by a national survey demonstrating that approximately 50% of paediatricians do not use developmental screening instruments (Glascoe & Dworkin, 1995). There are several reasons why professionals do not use screening tools. The most common reasons include: time constraints; the need for multiple tests based on biological, psychological, or environmental causes; the vast selection of screening tests; and screening tools are not regulated by professional societies (Rydz et al., 2005).

Rydz and colleagues (2005) reported on parent-completed developmental screening questionnaires. These researchers found that parent-completed questionnaires are just as accurate as paediatrician-completed questionnaires. These findings of accurate screening of child development were found regardless of parents' socioeconomic status, geographic location, or well-being (Rydz et al., 2005). The reliability and validity of parent-completed screening questionnaires have also been assessed. Reliability is highest when the questionnaires are presented in a well-structured manner, with specific, detailed, and well-worded questions (Glascoe & Dworkin, 1995).
**FASD Screening Tools**

Some community agencies have developed their own screening tools, primarily for program purposes and for assessment of suspected FASD in individuals. Although there is limited research on the psychometric properties performed on these measures to date, they warrant discussion as the primary goal is to screen individuals for the possibility of having FASD. These tools look at strengths and deficits in adaptive functioning as indicators of possible FASD. These tools include the FASNET, the Fetal Alcohol Behaviour Scale, and the FASCETS. Most commonly used are the series of FASNET checklists, designed to determine the need for referral, based on physical, cognitive, behavioural, and social indicators specific to various age groups (BC FAS/E Support Network).

**FASNET Screening Tool.** The FASNET Assessment Tool was developed by the BC FAS/E Support Network. It was developed to help identify individuals at risk and is intended for use by non-medical professionals and caregivers. The FASNET is not intended to be a diagnostic tool, although the publishers of the FASNET Screening Tool emphasize: “Information from this assessment should be used solely as an indicator in determining whether further assessment by medical professionals, competent to make Fetal Alcohol Syndrome/Effect diagnosis is warranted” (FASNET, 1995, p.2). They also point out that, “as a general rule, an individual whose mother drank alcohol during her pregnancy, and who has more than 50% of the items on this assessment tool checked off, should seek a medical assessment” (FASNET, 1995 p.2). The FASNET screens individuals for the presence or absence of adaptive functioning in the following areas: Communication/Language Use; Socialization; Behaviour; Attention; Activity and Impulsivity; Memory; Cognitive; Safety Issues; and Mental Health/Moral
Development/Maturity Issues. The person who completes the checklists is someone who is knowledgeable about the individual being assessed. This tool is very comprehensive and considers the individual’s history and physical findings, where possible.

A limitation of the tool is that it tends to repeat many of the items and requires a degree of judgement and interpretation regarding the exact meaning of some of the items. Since the responses are either “yes” or “no”, this tool leaves no room for variability on the responses and creates a blanket statement for the individual being evaluated.

Fetal Alcohol Behaviour Scale (FABS). The Fetal Alcohol Behaviour Scale (FABS) was developed by Streissguth and colleagues in 1996. This 36-item scale, in a yes/no format, describes the behavioural essence of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE), regardless of age, race, sex, or IQ. The FABS score is a simple count of yes responses. A person or caretaker who knows the patient the best completes the tool or it can be completed by the consensus of a group who collectively know the patient’s behaviour well. The FABS score has high item-to-scale reliability (Cronbach’s $\alpha = .91$), adequate test-retest reliably ($r = .69$), and has maximum usefulness across various groups from age 2 up through age 35 (Streissguth et al., 1998). FABS scores appear to be correlated with maternal alcohol problems, but not with paternal alcohol problems. Thus, the FABS appears to reflect the behavioural phenotype of fetal alcohol exposure fairly specifically rather than the behavioural consequences of being raised in an alcoholic family. The FABS also correlates moderately ($r = -.36$) with the Vineland Adaptive Behaviour Scale. Further studies are needed to clarify its utility in a clinical or screening context. The authors report that the FABS should not be used clinically without additional evidence of prenatal alcohol exposure. Additional studies are needed to determine the
specificity of this behavioural phenotype to alcohol teratogenesis, to evaluate contemporaneous interrater reliability, and to ascertain the conditions under which it would be a useful tool (Streissguth et al., 1998). Studies have not been completed to determine whether the FABS succeeds in capturing the specific behavioural essence of FAE and alcohol-related neurodevelopmental disabilities, compared with other developmental disabilities (i.e., Down syndrome) (Streissguth et al., 1998). In addition, the FABS is not available to agencies at this time, except by special arrangements with the authors (Ladue et al., 1999).

_FASCETS_. The FASCETS pre-screening tool was developed by Diane Malbin in 2000. This pre-screening tool was developed “to support the referral and diagnostic process and is not intended for diagnostic purposes. It is suitable for children, adolescents and adults and was designed for use by parents, teachers, and community partners” (Malbin, 2000, p.2). This tool was adapted from the Diagnostic Guide for FAS and Related Conditions, FAS Diagnostic and Prevention Network, University of Washington, 1999. The FASCETS screening tool is used by the rater rating the primary and secondary characteristics of FASD, and the tool captures the person’s strengths into the rating scale. This tool has been used for the past five years to support referral to the Oregon Neurodevelopmental Diagnostic Clinic. It is currently being field tested for reliability and validity (Daine Malbin, personal communication, May 2, 2005). Premji, Serrett, Benzies, and Hayden (2004) reviewed the FASCETS pre-screening tool and reported that Malbin’s (2000) study should be interpreted with caution due to the lack of information about the psychometric properties of the assessment form and due to the limited information that was provided to determine whether appropriate statistical analyses were undertaken.
The lack of standardized screening tools has led to detrimental practical problems for individuals, their families, friends, and service providers. Without standardized screening tools, individuals affected by FASD continue to face the challenges and difficulties of everyday living without adequately understanding why they have difficulty. They will continue to face the "revolving door" affiliation with social services or child protection services. They will continue to have difficulties in relationships with their partners, children, and professionals, as well as difficulties with employment and schooling. Services that have been developed for individuals who face other types of challenges do not meet the needs of FASD individuals because of their varying deficits, strengths, and skills, along with a unique complex of social, psychological, and health problems. Therefore, standardized tools are essential for identifying the health and well-being of individuals who are affected by FASD and identification, in turn, is essential for health and well-being.

The areas of greatest concern to clinicians and caretakers of adults with FASD are adaptive and social functioning (Ladue, Streissguth & Randels, 1992). Standard educational, parenting, and clinical techniques are based on learning theory, which maintains that people learn through experience and draw conclusions from observed cause and effect. Traditional programming and case management are not working effectively (Malbin, 1997). The reason why they are not working is the case management and intervention strategies that are being utilized are based on the premise that these adults learn easily. Recognition of the differences in brain functioning in individuals who are FASD affected and those who are not suggests the need to use a different approach (Malbin, 1997). Professionals working with FASD concur that environmental, not
behavioural, interventions are more successful for intervention outcomes (Rutman et al., 1996). A person limited to mobility in a wheelchair is accommodated through the removal of physical barriers. A person limited by FASD needs environmental accommodations as well.

*Structured For Success Project Screening Tool.* The SFSP needed a way to identify parents who would benefit from a multidisciplinary team approach to services and who would benefit from environmental accommodations. Therefore, SFSP developed a screening tool for two main purposes: first to establish eligibility for the project and second to support the referral for a diagnosis of FASD. The screening tool was developed after a preliminary literature review revealed that no assessment tool existed that was suitable for the purposes of the SFSP. A subcommittee of psychologists in Prince George, British Columbia, developed the screening tool based on their knowledge of FASD and on existing screening tools. The draft tool was brought to the community team, who provided real-life, concrete examples of each measure. Appending an "example sheet" to the tool is believed to increase the reliability of the tool and to assist in the completion of the form.

The screening tool has six primary areas: parent's strengths, history, primary characteristics, secondary characteristics, parents' health, and support network. The parent's strengths were included in the screening tool to capture an individual's abilities that could be built upon and supported during case planning. History includes questions about such subjects as foster placements, stability of living arrangements, past record of violence or trauma, developmental services, and maternal exposure to alcohol. These areas were included based on the risk and protective factors identified by Streissguth's (1996) longitudinal study on secondary disabilities. Primary and secondary characteristics are
rated on a likert scale from 1 to 5 with 1 = No, 2 = Rarely, 3 = Sometimes, 4 = Usually, and 5 = Always. Parent’s health category evaluated physical, nutrition, exercise, recreation, and stress management. The final category addressed the parent’s support network, where parents are asked to identify positive supports in their life.

This screening tool, designed to capture adaptive functioning, works from a strength-based approach to identify adults who might appropriately receive services from SFSP. The tool is simple (i.e., user friendly, not burdensome) and does not require significant training to complete. The screening tool is to be completed by a family worker who knows the family well or by collaborating information obtained from family or friends of the affected adult.

The tool is not intended for diagnostic purposes, but rather, is designed to be used with parents who have come to the attention of the Ministry of Children and Family Development (MCFD) with regard to child protection concerns and who are also receiving services from either Northern Health Addictions and Substance Use or Northern Health Adult Mental Health Services. The screening tool was designed to identify parents who might benefit from the SFSP. It needs to be sensitive enough to capture the adaptive functioning difficulties that are characteristic of parents with FASD and reliable enough that it can be relied upon to identify individuals who would benefit from referral for complete diagnosis.
Chapter Three

Present Studies

This study was designed to assess the degree of reliability of the Structured for Success Project (SFSP) screening tool, a brief screening tool intended to identify possible FASD. The data collected were comprised of responses to SFSP screening tools completed by service providers from the Ministry for Children and Family Development. The purpose of this study was to determine the psychometric properties of the instrument itself and the scores produced by the Structured for Success Project’s screening tool. The first purpose of the SFSP screening tool was to evaluate functioning of clients referred to the Structured for Success Project in Prince George, British Columbia, based on FASD characteristics. The second purpose of this tool is to identify individuals who may require a referral for an assessment querying a diagnosis of FASD. If reliable, the screening tool will also be used to determine the type and amount of special assistance that people with disabilities need. Although screening may offer a means of identifying those individuals who may benefit from a diagnosis, more importantly, screening is needed so that the window of opportunity is not missed for interventions to address maladaptive behaviours. In study one the screening tool’s construct validity is evaluated; Study two the screening tool’s internal consistency as well as the function of the rating scales is evaluated; and Study three the screening tools test-retest reliability is evaluated, along with comments and recommendations received from the participants regarding the screening tool.
Study One: Construct Validity

Overview

The purpose of study one was to examine construct validity of the SFSP screening tool. Generally, validity refers to the degree to which the item measures what it is intended to measure (Streiner & Norman, 1995). Usually the evaluation of construct validity focuses on whether test items are essential for the test’s purpose (Streiner & Norman, 1995). Messick (1988) presented a unified and expanded theory of validity, which included the evidential and consequential bases of test interpretation and use. The evidential basis for validity includes both test score interpretation and test score use. The evidential basis for interpreting tests involves the empirical study of construct validity, which is defined by Messick (1998) as the theoretical context of implied relationships to other constructs. The evidential basis for using tests involves the empirical investigation of both construct validity and relevance/utility. Different approaches are available to assess construct validity. A team of professionals in Prince George, British Columbia, developed the SFSP screening tool for the Structured for Success Project. The team consisted of six psychologists and paraprofessionals who constructed the tool based on relevant scientific and professional literature and their judgements as content experts. The SFSP screening tool was designed at the time to be used for program entry and to determine if future referrals for diagnoses were necessary. After the tool was drafted, the researcher was asked to test the psychometric properties of the screening tool.

Measures

The SFSP screening tool consists of six sections; Strengths, Additional Factors, Primary Characteristics, Secondary Characteristics, Health, and Support Network. The
Primary and Secondary Characteristics are the quantitative portions of the screening tool and were evaluated in the present research. The Primary Characteristic scale is comprised of 24 items describing the primary characteristics of FASD. The Secondary Characteristics scale is comprised of 19 items describing the secondary characteristics of FASD. All these items are rated on a 5-point scale, 1 = No, 2 = Rarely, 3 = Sometimes, 4 = Usually, 5 = Always, or marked N/A = Not Assessed. Each characteristic listed is followed by several examples to assist in rating the item. Examples from the Primary and Secondary Characteristics subscales are provided below.

Primary Characteristics subscale

**Has difficulties with interpersonal skills – Socially awkward – is disruptive, intrusive, awkward, doesn’t share or take turns; does annoying things that “bug” others; doesn’t know when to quit; does not make the connection between socially unacceptable behaviour and consequences; misunderstands social cues.**

Secondary Characteristics subscale

**Is overly trusting, Is easily manipulated or victimized - is victimized, teased, bullied, intimidated by others; is easily taken advantage of; is gullible, easily set up, influenced, coerced; is too trusting, naive**

Along with the SFSP Screening Tool, raters are given an example-screening tool to support the completion of the tool. See below for an example.

**Has problems transferring knowledge**

*Has difficulty generalizing from one situation to another; does not learn from past experience; is unable to see cause and effect or to anticipate outcomes*

Worker explains to parent that she/he should not be spanking her/his child in Zellers. The Worker later receives a call that the parent is spanking the child in Sears.

*Parent likes to have candles burning in the living room, but can not see the danger in reaching over them with long drapery sleeves or in allowing children to throw toys in the room or even in allowing children to play with them.*
**Procedures**

To examine the SFSP screening tool’s construct validity, the researcher found empirical articles on FASD in adulthood through the PsychInfo database. As well, to locate additional documentation, the researcher reviewed professional resources and materials such as parenting manuals written for parents affected by FASD. Only those items discussing primary characteristics were evaluated for construct validity for two reasons. Firstly, the literature defines primary characteristics as the direct product of brain damage from prenatal exposure to alcohol, whereas secondary characteristics are defined as the result of the primary characteristics in interaction with environment (Streissguth & Kante, 1997). Secondly, there is insufficient research at this time in the area of secondary characteristics of FASD in adulthood (Chudley et al., 2005). After reviewing the articles on adulthood and FASD, the researcher identified the primary characteristics in the literature and compiled in Appendix E containing research to support each primary characteristic.

**Results**

Of the 24 items on the Primary Characteristics subscale, 19 are adequately supported by empirical evidence (see Appendix E). The items and supporting citations are listed in Appendix E. The items with the most evidence of construct validity included Item 2 (Shows organizational difficulties with follow through, problems with sequencing), Item 4 (Has problems transferring knowledge), Item 7 (Is impulsive, distractible), Item 10 (Requires additional processing thinking time), and Item 20 (Has challenges with generalizing and transferring information). The remaining 5 items were mentioned in professional resources and materials but not in empirical research. These 5 items included Item 3 (Has problems accommodating requests of other people), Item 12 (Is persistent),
Item 13 (Has difficulty saying no and setting personal limits), Item 17 (Has difficulty with concepts such as ownership, honesty), and Item 18 (Makes irrelevant statements).

Discussion

The SFSP screening tool demonstrated moderate construct validity with the exception of the five items shown in Appendix E. These 5 items were mentioned in professional resources and materials but were not well documented within the empirical-based literature. There is concern regarding the participant pool of the empirical research to date, in that the majority of the research resulted from Streissguth’s work in Washington, DC. Considering the minimal empirical research in the area of adults affected by FASD and the extensive clinical and professional experience captured in professional resources and materials, future research may well document findings that pertain to these items. At present, however, the construct validity of those 5 items as measures of primary characteristics of FASD is in question.

Study Two: Internal Consistency

Overview

Study Two was designed to determine if the Structured for Success Project screening tool is a reliable measure that could be used by service providers in a time efficient and consistent manner. Study Two had two objectives. The first objective was to test the internal consistency of the scores produced by the SFSP screening tool. Internal consistency assesses whether all items measured the same thing.

The second objective was to assess the rating scale categories using the Rasch analysis (Rasch, 1960). The Rasch analysis is an investigation into the functioning of the rating scale categories. Rating scale categories should be well defined, mutually exclusive,
univocal, and exhaustive (Guilford, 1965). Because there is always uncertainty about how a rating scale was used by individuals in a sample, an investigation of the functioning of the rating scale is always necessary (Linacre, 2002), and can be done with the Rasch analysis. The Rasch rating scale model (Rasch, 1960; Andrich, 1996), actualized using the computer program WINSTEPS (Linacre & Wright, 1999), provides an effective framework within which to verify, and perhaps improve, the functioning of rating scale categorization. In the Rasch analysis, a useful diagnostic in evaluating category usage is to examine the average measure and threshold of each category. The average measures across categories represent the empirical averages of the measure (Rasch trait or ability score) that are modeled to produce the responses observed in Rasch categories (Linacre & Wright, 2000). Because observations in higher categories must be produced by higher measures, the average measures across categories must increase monotonically. The thresholds indicate the measures at which adjacent categories are equally probable and thus define the boundaries between the categories. Therefore, the thresholds too should increase monotonically.

Participants

There were two sources of participants. The first source consisted of 47 service providers (42 females, 5 males) who volunteered to participate and were recruited from the Ministry of Children and Family Development (MCFD) in Prince George, British Columbia. The second source was from 18 screening tools that were previously completed for program entry for the Structured for Success Project. In total, data were collected from 65 completed SFSP screening tool forms. Most participants worked in the child protection field with the exception of five participants, who worked in the youth probation department of MCFD.
Measures & Procedures

The Structured for Success Project screening tool as described in Study 1 was used in the Study 2. For the 47 participants from MCFD, the service providers had to have worked with a parent who was either diagnosed with FAS or FAE or who was suspected of being prenatally exposed to alcohol. Each participant was instructed to complete the screening tool to the best of his/her knowledge. There was no identifying information taken about the parents for the screening tools. The screening tools were completed for parents who were suspected of having FASD or had been diagnosed with FAS or FAE. Although the screening tools were administered to participants in groups ranging in size from 5 to 9 (median = 7), all participants were instructed not to share their information with their co-workers. All participants were assured of anonymity and informed that their data would be used for research purposes only.

The 18 completed SFSP screening tool forms from the SFSP were about parents who were referred for program entry to Structured for Success Project. The Ministry for Children and Family Development gave permission to use the above-mentioned screening tools for research purposes. The letter of information and request for documentation forwarded to the Ministry of Children and Family Development is presented in Appendix B. All participants completed informed consent forms outlining the risks and benefits of this research study. There was no identifying information taken from the screening tools and no parents’ names were used. Service providers were given detailed instructions with examples for each Primary and Secondary Characteristic to guide their completion of the tool.
Data Analysis

The data from the screening tools were entered into an EXCEL© file on a secure computer with a secure password for access. All screening tools were identified with a code number ranging from 01 to 65. Using ITEMAN© (Assessment Systems Corporation, 2000), internal consistency was calculated as Cronbach’s Alpha. Additional statistics include item and scale means, item and scale variability, and item-scale correlation. Testing of the screening tool’s scales was completed with Rasch analysis using the WINSTEPS program (Linacre & Wright, 2000).

Results

Descriptive and reliability statistics are presented in Appendix F for the total sample. The internal-consistency reliability analysis (ITEMAN©) showed moderately high Cronbach alpha (.84) for Scale 1 (24 items). The internal consistency reliability analysis showed moderately high Cronbach alpha (.85) for Scale 2 (19 items). The researcher examined the internal-consistency of the SFSP screening tool using a combined scale as well. The internal consistency reliability analysis showed high Cronbach alpha (.91) when treating the subscales as one scale. This analysis was performed because the Primary and Secondary subscales are always administered as one tool. Although the psychometric properties of the SFSP screening tool were assessed as one scale, final discussions will focus on the results of the Primary and Secondary Characteristics subscales separately. This decision is based on the purpose of tool and the nature of the differences between primary and secondary characteristics associated with FASD.

Corrected item-scale correlations were calculated to examine the correlation of individual items with the overall score. There were 43 correlations; these include the
Primary Characteristics subscale of 24 items and the Secondary Characteristics subscale of 19 items. The corrected item-scale correlations were corrected for test items from the total score before calculation to avoid inflating the correlations. An example, item 11 “Shows limited awareness of boundaries” from the Primary Characteristics subscale had a correlation of 0.65. This item is performing well and is demonstrating a strong relationship with the other test items. There were four items from the Primary and Secondary Characteristics subscales with correlations less than .30. These items included Item 9 “Has problems with spatial orientation”, Item 22 “Talks excessively”, Item 1 “Is overly trusting, is easily manipulated or victimized”, and Item 3 “Easily Fatigued”. The first two items are drawn from the Primary Characteristics subscale. Item 9 “Has problems with spatial orientation” is well documented in literature (Conner et al., 2000; Conner & Streissguth, 1996; Gardner, 2000; Streissguth, 1994). However, Item 22 “Talks excessively” is not well supported in the literature. Based on the literature and on the low item to scale correlation, it would be suggested that Item 22 be removed from the SFSP screening tool. As the Secondary Characteristic subscale was not tested for construct validity, the researcher must solely rely on the scores produced to determine the effectiveness of Items 1 and 3 from the Secondary Characteristic subscale of the SFSP screening tool, and therefore will retain these items further analysis.

After the analysis of the Primary and Secondary subscales treated as one scale there were six items that had item-scale correlations below .30. These included Item 8 “Has problems with time and schedules”, Item 9 “Has problems with spatial orientation”, Item 14 “Needs prompting to complete tasks”, and Item 22 “Talks excessively”. From the Secondary subscale Item 1, “Is overly trusting, is easily manipulated or victimized”, and
Item 3, Easily fatigued”. Although the internal consistency was higher with one scale, there were more test items with lower corrected item-scale correlations. The low correlations maybe due to greater variability on the Secondary Characteristics subscale relative to the scores on the Primary Characteristics subscale. The scores on the Primary Characteristics subscale will be similar across all affected adults, but scores on the Secondary Characteristics subscale will be more variable depending on life experiences and supports each person has had. For example with intervention and support the secondary characteristic test item scores should lessen, thus creating changes within the item-scale correlations.

The second purpose of this study was to determine if the rating scale categories are performing as expected. Linacre (2002) developed eight guidelines for optimizing rating scale category effectiveness using Rasch analysis. The SFSP screening tool was evaluated according to the eight guidelines.

Guideline 1- At least 10 observations of each category. This guideline is straightforward in stating that there must be more than 10 observations in each category for a stable scale structure. The five categories used in the SFSP screening tool each contained no less than 109 observed counts. See Table 1 for the observed counts for the Primary Characteristics subscale and Table 2 for the Secondary Characteristics subscale. All the category frequency counts are large, indicating that locally stable estimates of the rating scale structure were produced.
Table 1  
Analysis of the Primary Characteristics of SFSP Screening Tool 

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<th>Category Count</th>
<th>Average Measure</th>
<th>Expected Measure</th>
<th>OUTFIT MnSq</th>
<th>Step Calibration</th>
<th>Coherence M-&gt;C</th>
<th>Coherence C-&gt;M</th>
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Table 2  
Analysis of the Secondary Characteristics of the SFSP Screening Tool  

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<td>1</td>
<td>122</td>
<td>-5.24</td>
<td>-5.73</td>
<td>1.18</td>
<td>NONE</td>
<td>50%</td>
<td>1%</td>
</tr>
<tr>
<td>2</td>
<td>188</td>
<td>-2.78</td>
<td>-2.62</td>
<td>1.15</td>
<td>-8.52</td>
<td>35%</td>
<td>36%</td>
</tr>
<tr>
<td>3</td>
<td>322</td>
<td>0.49</td>
<td>0.53</td>
<td>0.81</td>
<td>-6.44</td>
<td>38%</td>
<td>62%</td>
</tr>
<tr>
<td>4</td>
<td>294</td>
<td>3.57</td>
<td>3.95</td>
<td>1.04</td>
<td>3.11</td>
<td>37%</td>
<td>44%</td>
</tr>
<tr>
<td>5</td>
<td>166</td>
<td>9.26</td>
<td>8.67</td>
<td>0.94</td>
<td>11.85</td>
<td>70%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Guideline 2 - Regular observation distribution. Guideline 2 states that a uniform distribution of observations across categories is optimal for step calibration. On the Primary Characteristics of the SFSP screening tool, each category shows a uniform distribution of observations across categories. The peak of the distribution is seen at
category 3 with 414 observed counts and at category 4 with 514 observed counts. As shown in Table 1, there is a reassuringly smooth distribution.

On the Secondary Characteristics of the SFSP screening tool, each category shows a uniform distribution of observations across categories. The peak of the distribution is seen at category 3 with 322 observed counts. As shown in Table 2, the frequency distribution is unimodal and shows a reassuringly smooth distribution.

**Guideline 3 – Average measures advance monotonically with category.** For both the Primary and Secondary Characteristics of the SFSP screening tool, the categories are advancing monotonically up the rating scale. Tables 1 and 2 display the Average Measure for each category. The Primary Characteristics categories steadily advance from -5.70 to 9.75. For the five categories of the Secondary Characteristics, the observed count progressively increases from -5.24 to 9.26.

**Guideline 4 – Outfit mean squares less than 2.0.** For the Rasch model, mean-square fit statistics have been defined to have the model-specified uniform value of randomness indicated by 1.0 (Wright & Panchapakesan, 1969). Studies indicate that values above 1.5 are problematic due to unexplained randomness and that values greater than 2.0 suggest that there is more unexplained noise than explained noise, indicating that there is more misinformation than information in the observations (Smith, 1996).

The Primary Characteristics subscales five categories have OUTFIT mean squares ranging from .86 to 1.11. For the Secondary Characteristics subscale, OUTFIT mean squares ranged from .81 to 1.18. There are no concerns with the mean squares fit statistics in this sample of observations.
Guideline 5 – Step-calibration advance. This guideline is an essential conceptual feature of the rating scale design in that increasing amounts of the underlying variable in a respondent correspond to increasing probabilities of the respondent being observed in higher categories of the rating scale (Andrich, 1996). In other words, as measures increase, or as individuals with incrementally higher measures are observed, each category of the scale must be designed to be more likely to be chosen. This assertion corresponds to the probability curves, which should look like a range of hills, with extreme categories approaching a probability of 1.0. Figure 1 exhibits the probability curves of the Primary Characteristics subscale and Figure 2 exhibits the probability curves of the Secondary Characteristics subscale. For both subscales, the extreme categories (i.e., Categories 1 & 5) are approaching 1.0, as can be seen in Figures 1 and 2.

The requirement for this type of inferential interpretability of a rating scale is that the Rasch step calibrations advance monotonically with the categories; in other words, as the category increases the step calibration must increase. In Table 1, the step calibrations for the Primary Characteristics are ordered from -9.38 to 15.04. In Table 2, the step calibrations for the Secondary Characteristics are also ordered -8.52 to 11.85. These results indicate that the rating scale has good psychometric qualities in that, when higher measures are observed, higher ratings are chosen.
Primary Characteristics

![Probability curves of primary characteristics subscale.](image_url)

*Figure 1.* Probability curves of primary characteristics subscale.
Figure 2. Probability curves of secondary characteristics subscale.
Guideline 6 – Ratings imply measures, and measures imply ratings. For a rating scale, it is vital that a single observation implies an equivalent underlying measure. Similarly, from an underlying measure, it is inferred what behaviour can be expected, and so, in general, what rating would be observed on a single item (Linacre, 2002). In Tables 1 and 2, the “Coherence” columns report on the empirical relationship between ratings and measures for the SFSP screening tool data. The column labelled M->C (Measure implies Category) shows what percentage of the measures that were expected to produce observations in each category actually did. The column labelled C->M (Category implies Measure) shows what percentages of the observations in each category were produced by measures corresponding to the category. Linacre (2002) states that 40% is an empirically useful level of coherence for satisfactory data sets. Generally, the categories for both the Primary and Secondary Characteristic scales are in the region of the 40% coherence level.

The Primary Characteristics scale generally produced good M->C results. However, it should be noted, that for C->M results, category 1 was 7% and category 5 was 9%. These percentages are low when inferring ratings to measures. After considering all the results of the rating scale, these percentages may be related to how the categories overlap with each other. In particular, as seen in Table 2, category 1 on the Secondary Characteristics scale demonstrated low C->M results; only 1% of the occurrences of category 1 were placed by the measures in category 1. This may be explained by the small sample size and the overlap seen in the probability curves of categories 2, 3, and 4. See Figure 2.

Guideline 7 – Step difficulties advance by at least 1.4 logits. It is helpful to communicate location on a rating scale in terms of categories below the location and categories above the location; this conceptualizes the rating scale as a set of dichotomous
items (Andrich, 1996). For practical purposes, when all step difficulty advances are larger than 1.4 logits, then a rating scale can be broken down, theoretically, into a series of independent dichotomous items. See Tables 1 and 2 for the step calibration for Primary and Secondary Characteristics subscales. For the Primary Characteristics subscale, the logits from categories 3 to 4 were -8.91 and for categories 4 to 5 were -13.42. Based on this guideline, the results indicate that from categories 3 to 4 and from 4 to 5 there is a sufficiently large gap between categories. For the Secondary Characteristics subscale, the logits from category 3 to 4 were -9.55 and from 4 to 5 were -8.74. These values are found, for example, by taking the value from category 3 and subtracting from the value of category 4. These values are calculated for each step calibration of categories.

Guideline 8 - Step difficulties advance by less than 5.0 logits. When a category represents a very wide range of performance, so that its category boundaries are far apart, then a dead zone develops in the middle of the category in which measurement loses its precision (Andrich, 1996). When the distance between step calibrations is more than 5 logits, the information provided at the item’s center is less than half that provided by a simple dichotomy. A discovery of a wide intermediate category suggests that it may be productive to redefine the category as two narrower categories (Linacre, 2002). As reported in guideline 7 above, the large logits difference between categories 3 and 4 and between categories 4 and 5 for both subscales may indicate the need to redefine these categories into a 7-point scale. Future studies with a larger sample will be needed to determine whether it is worthwhile to reconstruct the rating scale to a 7-point scale.
Discussion

The main objectives of study 2 were to evaluate internal consistency of the SFSP screening tool and to assess the rating scales categories of the tool. Study 2’s results summarize key characteristics of the SFSP screening tool’s reliability. In particular, internal consistency and the functions of the rating scale’s categories were evaluated. Cohen (1960) stated that the widely-accepted social science cut-off for internal consistency should be an alpha of .70 or higher for a set of items to be considered a scale, but some use .75 or .80 while others are as lenient as .60. The results from Study 2 indicate that the SFSP screening tool has moderately high internal consistency. Cronbach’s alpha for both subscales of the SFSP screening tool can be interpreted as providing sufficient preliminary evidence for the overall reliability of the tool. Streissguth and colleagues (1998) found that the Fetal Alcohol Behaviour Scale (FABS) demonstrated high reliability, Cronbach’s alpha = .91. The SFSP screening tool’s internal consistency is comparable with the measure produced by Streissguth and colleagues (1998).

Traditionally, in psychology a large correlation is considered to be about .50 or above, a moderate correlation to be about .30, and a small correlation to be about .10 (Aron & Aron, 2003). Four of the 43 items on the SFSP screening tool had corrected item-scale correlations below .30. Two of the items were from the Primary Characteristics subscale; these were Items 9 and 22. Item 9 “Has problems with spatial orientation” is well documented in literature (Conner et al., 2000, Conner & Streissguth, 1996, Gardner, 2000; Streissguth, 1994); however, Item 22 “Talks excessively” is not well supported in literature. Based on the absence of supporting literature and on the low corrected item-scale correlation, it is suggested that Item 22 be removed from the SFSP screening tool. Item 9
should be retained for future testing. The two items from the Secondary Characteristics subscale were: Item 1 "Is overly trusting, is easily manipulated or victimized" and Item 3 "Easily fatigued." There is currently insufficient research in the area of secondary characteristics to support the construct validity of these and other items. Further studies with larger sample sizes and more research in the area of secondary characteristics in adulthood will be needed to warrant removal of Item 9 from the Primary Characteristics subscale and Items 1 and 3 from the Secondary Characteristics subscale. Overall, the internal consistency of the SFSP screening tool produced moderate results indicating it is a reliable tool.

In general, the SFSP screening tool rating scale categories are working as expected. The SFSP screening tool meets the majority of the guidelines proposed by Linacre (2002). There is evidence that the SFSP screening tool rating scale categories are sufficient for accurately measuring the Primary and Secondary Characteristics associated with FASD. Several characteristics emerged as key features of the rating scale in this study. Both scales had at least 100 observations in each category, a feature essential for measure stability, measure accuracy, description of the sample, and for inference to the next sample. The results indicated a regular distribution for each scale, also essential for measure stability.

A rating scale, in general, must produce higher measures from observations in higher categories if users are to know what a higher measure means. The SFSP screening tool displayed ideal results as the measures advanced monotonically with the categories. In other words, when an individual gave a rating of 4 it was seen as a higher measure of the characteristic of FASD than was a rating of 3. The Rasch model specifies that a reasonable uniform level of randomness must exist throughout the data and is essential for
measurement accuracy (Linacre, 2002). Concerns should arise when the mean-square values are greater than 1.5 because of unexplained noise in the data; in this study, the evidence supports the conclusion that the scales exhibit good predictability.

A fundamental feature of rating scale design is that as individuals with incrementally higher measures are observed, each category of the scale must in turn be designed to be most likely to be chosen (Linacre, 2002). This effect was seen graphically in Figures 1 and 2 of the probability curves. Based on this evidence, the five categories for each scale display accurate results. The extreme categories of the SFSP screening tool (Categories 1 and 5) approach the probability of 1.0, as the model specifies that respondents with high (or low) measures must be observed in the highest (or lowest) categories. As well, categories 2, 3, and 4 visually display unique high points on the measured variables and each category has distinct curves that represent “rolling hills”. Further categories 2 to 4 have a similar range (person’s logits) between each scale unit.

The guidelines that raised questions about the SFSP screening tool were ratings that imply measures and step difficulty. These guidelines are not essential for measure stability or accuracy but are helpful for inference for the next sample (Linacre, 2002, p. 275). Although the Primary Characteristics rating scale produced low diagnostics for categories 1 and 5 and for category 1 of the Secondary Characteristics rating scale, little weight should be placed on redefining the scale at this time. These results may be explained by the sample size and the overlap seen in the probability curves of the categories. Furthermore, some of the categories on each scale exhibited large boundaries. For example, on the Primary Characteristics scale, the step calibration from categories 3 to 4 was -8.91. These large distances may indicate that the scale is providing less information about the respondents.
apparently targeted best by the scale and, in fact, suggest that the scale is better at probing respondents at lower and higher decision points than at the center. Researchers have noted, however, that scale refinement is usually not required in order for valid and inferentially useful measures to be constructed from rating scale observations (Andrich, 1996). This guideline should be evaluated in future studies with larger samples before the rating scale is redefined into a 7-point scale.

The statistics reported guided the assessment of how the categories function and indicate whether the rating scale created an interpretable measure. Based on these statistics, we can conclude that the SFSP screening tool rating scale is an interpretable measure with stable and accurate estimates. The rating scale developed for this tool divulges reliable and sufficient scores that could be used to meet the objectives of the SFSP screening tool.

Study Three: Test-Retest Reliability

Overview

For Study 3 an evaluation of the SFSP screening tool test-retest reliability was conducted. This evaluated the stability over time of the scores produced by the screening tool. In addition, the researcher collated participants' comments and recommendations about the SFSP screening tool.

Participants

The sample consisted employees from the Ministry for Children and Family Development; however, there were 6 participants who were not able to complete the second part of the research. Therefore, the final sample was from 41 service providers from the Ministry for Children and Family Development from Prince George, British Columbia,
who each filled out screening tools on two occasions, yielding data from 82 completed SFSP screening tool forms.

Measures

The SFSP screening tool, as described in Study one, was used in the study of test-retest reliability.

Procedures

The participants completed SFSP screening tool forms regarding parents who were either diagnosed with FAS or FAE or who were suspected of having FASD. The service providers rated the same parent twice over an interval of one month. These service providers volunteered to participate in the research and were asked to sign an informed consent form outlining the risks and benefits of their participation. After the instructions for completing the form were given, each service provider was asked to provide a hint to assist their memory for part two of the data collection. This was necessary because the parent’s names were not recorded; at Time 2 the hints were used to remind service providers of which parent they had rated at Time 1. To ensure completion and accuracy, service providers were asked to complete the screening tool during a pre-arranged group meeting, which took place in the morning and on the same day of the week. One month later, at which time they were provided with their hint, the service providers were asked to complete the second part of the data collection regarding the same parent. The mean of the test-retest interval for the present study was 32.6 days and the median was 34 days.

The comments and recommendations regarding the SFSP screening tool were accumulated informally during data collection for Studies 2 and 3; these comments and recommendations were gathered from the sample of 47 participants.
Data Analysis

The data from 82 screening tools were entered into an EXCEL© file on a secure computer with a secure password for access. All screening tools were identified with a code number ranging from 01 to 41 for Time 1 and Time 2. Mean scores for Time 1 and Time 2 for both Primary and the Secondary Characteristics subscales of the SFSP screening tool were calculated allowing for up to two missing data points per subscale. Using SPSS©, test-retest reliability was tested with the use of correlations.

Results

The means and standard deviations for the Primary and Secondary Characteristics subscales appear in Table 3. The correlation between Time 1 and Time 2 for the Primary Characteristics subscale was significant, \( r = .77, p < .001 \). The correlation between Time 1 and Time 2 for the Secondary Characteristics subscale was significant, \( r = .71, p < .001 \). The Primary and Secondary Characteristics subscale scores were equally stable across the one month interval, \( z = 0.55 \ ns \). This indicates that secondary characteristics were not significantly less stable than primary characteristics over the period of one month. Test-retest reliability was performed as one scale (Primary and Secondary Characteristics) together. The correlation between Time 1 and Time 2 for both the Primary and Secondary Characteristics subscales was significant \( r = .748, p < .001 \).
Table 3

Mean and Standard Deviations for the Primary and Secondary Characteristics at Time 1 and Time 2

<table>
<thead>
<tr>
<th>SFSP Screening Tool</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 1</td>
<td>3.46</td>
<td>0.55</td>
<td>42</td>
</tr>
<tr>
<td>Time 2</td>
<td>3.41</td>
<td>0.61</td>
<td>41</td>
</tr>
<tr>
<td><strong>Secondary Characteristics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 1</td>
<td>3.29</td>
<td>0.67</td>
<td>42</td>
</tr>
<tr>
<td>Time 2</td>
<td>3.28</td>
<td>0.61</td>
<td>41</td>
</tr>
</tbody>
</table>

Informal comments and suggestions regarding the SFSP screening tool were collected from direct conversations with participants during the data collection process. In particular, service providers provided verbal suggestions that are useful for future recommendations. In general, service providers had difficulties rating some of the questions, as it was not clear whether the items occurred throughout the lifespan or for a limited time. For example, a parent may have had a drug and alcohol problem in the past but had remained sober for the past 5 years. Clarification is needed on how to rate historical versus current aspects of functioning. Another recommendation was to display the rating scale on the top of every page of the SFSP screening tool to increase accuracy and efficiency when completing the tool. Comments regarding individual items follow:

Item 9 “Has problems with spatial orientation”: participants were not able to assess this characteristic,
Item 10 “Is disruptive at school or at work”: participants commented that this item was not relevant for many of their clients,

Item 13 “Trouble at home”: participants found this item difficult to assess on an individual basis,

Item 15 “legal system involvement”: participants asked for clarification between family and criminal court proceedings, and

Item 17 “Unplanned pregnancy”: participants suggested that this be answered as either yes or no.

Discussion

The SFSP screening tool demonstrates good test-retest reliability. Thus, the SFSP screening tool is similar with greater reliability results than the Fetal Alcohol Behaviour Scale (FABS) where test-retest reliability is $r = .69$ (Streissguth et al., 1998). Aron and Aron (2003) contest that, within the discipline of psychology, a reliable measure should have test-retest reliability of at least $r = .60$, and that, for clinical tools that measure stable constructs, the correlation should be preferably closer to $r = .90$. Therefore, the present study indicates that the SFSP screening tool is a moderately stable screening tool for the purposes of screening for SFSP program entry and for identifying a need for a referral for a medical diagnosis.

Feedback received from the service providers provided important guidance in two main areas. Firstly, in the area of historical ratings, participants asked for clarification regarding when to incorporate the parent’s past history and when not to. Secondly, service providers felt that reformatting the SFSP screening tool with the rating scale appearing on
the top of each page of the tool would be beneficial for accuracy and efficiency. These suggestions are manageable, fair, and understandable.
Chapter Four

General Discussion

The purpose of this study was to test the psychometric properties of the SFSP screening tool. There were 3 studies conducted, evaluating the screenings tool’s construct validity, internal consistency and rating scale functions, and test-retest reliability. The Structured for Success Project is a community health initiative in Prince George, British Columbia, that offers services to parents who may be affected by FASD. The SFSP screening tool was developed to screen adults who may be affected by FASD. The SFSP screening tool was designed for use by service providers to rate the Primary and Secondary Characteristics that are consistent with someone affected by FASD. Items on the Primary Characteristics subscale refer to an individual’s learning, developmental, and/or physical responses to the environment and other behavioural symptoms that are associated with prenatal exposure to alcohol. Items on the Secondary Characteristics subscale refer to defensive or reactive behaviours that are a result of frustration and failure (Rutman, LeBerge, & Wheway, 2002). The data reported in the present studies are based on the scores produced by the Primary and Secondary Characteristics scales of the SFSP screening tool.

The specific aims of the present study were to examine the psychometric properties and construct validity of the SFSP screening tool. Specifically, internal consistency, properties of the rating scale categories, and test-retest stability were evaluated. Using these evaluation criteria, the studies reported herein provide evidence that the SFSP screening tool is reliable. The data on the SFSP screening tool also provide partial support for the construct validity of the measure. The findings provide preliminary evidence that the SFSP
screening tool can be used for determining program entry into the Structured for Success Project, to develop individual case plans for parents, and to identify parents who may require a referral for a diagnosis of FASD.

The results from Study 1 support initial construct validity of the SFSP screening tool. Construct validity was evaluated in the present study by a review of the literature for adults with FASD. The Primary Characteristics subscale consisted of 24 items, 19 of which demonstrated satisfactory construct validity. The items most strongly supported by existing research include Item 2 “Shows organizational difficulties with follow through and problems with sequencing,” Item 4 “Has problems transferring knowledge,” Item 7 “Is impulsive, distractible,” Item 10 “Requires additional processing thinking time,” and Item 20 “Has challenges with generalizing and transferring information.” There were five items of the SFSP screening tool that demonstrated questionable construct validity. These five items included Item 3 “Has problems accommodating requests of other people,” Item 12 “Is persistent,” Item 13 “Has difficulty saying no and setting personal limits,” Item 17 “Has difficulty with concepts such as ownership, honesty,” and Item 18 “Makes irrelevant statements.” These five items may have low construct validity because of the limited research regarding adults affected by FASD. Another indication of low construct validity for the indicated items of the scale may be the ambiguity of the characteristics; for example, Item 18 “makes irrelevant statements,” can be interpreted differently by different raters, depending how well the rater knows the client. Based on restricted research of the life-long outcomes of FASD, further investigation of the validity of the SFSP screening tool would be required before removal of these five items is recommended.
Researchers have indicated that an individual with FASD has compromised adaptive functioning. Adaptive functioning consists of independent functioning, social functioning, and school or vocational functioning (Sparrow, Bella, & Ciccehetti, 1984). A person’s adaptive functioning increases by learning new skills and by adjusting to environmental surroundings, and an individual’s adaptive behaviour generally increases and becomes more complex with age. However, when an individual has had prenatal exposure to alcohol, his/her adaptive functioning is affected. Streissguth and colleagues (1998) report that social and adaptive skills are considered the most important areas to assess for adults affected by FASD. Yet there are currently no available standardized instruments to measure the unusual adaptive problems found in FASD (Legge, Roberts, & Butler, 2000).

The internal consistency of the SFSP screening tool presented important findings for the usefulness of the measure. The values of Cronbach alpha for the Primary Characteristics subscale and the Secondary Characteristics subscale were satisfactory. This implies sufficient internal consistency of the SFSP screening tool for the outlined purposes of the measure. Two screening tools were identified in the literature review; these included the FABS and the FASCETS. The FABS reported high internal consistency; however the authors reported they have completed studies to determine whether the FABS succeeds in capturing the specific behavioural essence of FAE and alcohol-related neurodevelopmental disabilities. The FASCETS measure was developed for use with the adult FASD population; however, due to the limited information about the psychometric properties in the literature, the researcher is unable to comment on the tool’s reliability or validity at this time.
Item-scale correlations were examined for all 43 items of the SFSP screening tool. Only two items from the Primary Characteristics subscale had low corrected item-total correlations. The construct validity of Item 9 “Has problems with spatial orientation” is supported by the literature (Conner et al., 2000, Conner & Streissguth, 1996, Gardner, 2000; Streissguth, 1994); however, the construct validity of Item 22 “Talks excessively” is not well supported. Due to the inconsistencies in the literature and the present reliability findings, it is recommended that Item 22 be removed from the SFSP screening tool. Two items from the Secondary Characteristics subscale had low item-total correlations. However, there is insufficient research in the area of secondary characteristics to support or deny these items at this time, and, therefore, the two items should be retained in the SFSP screening tool. Further psychometric studies with larger samples and more research in the area of secondary characteristics in adulthood will be needed before recommending removal of Item 1 “Is overly trusting, is easily manipulated or victimized” and Item 3 “Easily fatigued” from the SFSP screening tool. Overall, the internal consistency and item-total correlations of the SFSP screening tool produced moderate results indicating a reasonably reliable measure. Because the characteristics of FASD are broad in nature, the tool’s reliability is considered adequate for the outlined purposes.

It is common knowledge that the way each rating scale is constructed has a great influence on the quality of data obtained from the scale (Clark & Schober, 1992). The rating scale categories for the SFSP screening tool based on the Rasch model are performing well, generally. The rating scale scores indicate the ability to facilitate interpretable measures. Findings of the SFSP screening tool rating scale produced measure stability and accuracy. Measure stability was shown as the scores from the rating scale
monotonically increased with the scale. In other words, a measure of 2 was greater than a measure of 1 and a measure of 3 was greater than a measure of 2 and so forth. Furthermore, the extreme categories (Categories 1 and 5 of the SFSP screening tool) should reach the probability of 1.0. There were two considerations based on the scores produced by the rating scale categories. First, the scores displayed ambiguous findings for category 1 and for category 5. These scores were less successful when inferring ratings to measures. After considering all the results of the rating scale, these scores may be related to how the categories overlap with each other and the fact that these are the extreme categories of the ratings. Second, the step difficulties for some of the categories displayed large boundaries; this may imply that the scale provides less information about the respondents’ answers. These large gaps were seen between categories 3 and 4 and from categories 4 and 5 for both the Primary and Secondary Characteristics subscales. For the rating scale, it is vital that a single observation imply an equivalent underlying measure. Similarly, from an underlying measure is inferred what behaviour can be expected, and so, in general, what rating would be observed on a single item (Linacre, 2002). The SFSP screening tool rating scale fit the Rasch model comparatively well based on the research by Linacre (2002) and Rasch (1960).

Data regarding the use of the rating scale’s categories suggests its appropriateness for use by service providers. The rating scale format is especially easy to use and reliability can be established with minimal training. To complete the SFSP screening tool a basic understanding of FASD is required in combination with the SFSP screening tool instruction guide. The SFSP screening tool has a user-friendly format, is cost efficient, and the rating scale appears to be useful in evaluating characteristics. The results from Study 3 support
that the SFSP screening tool has good test-retest reliability, in that the Primary and Secondary Characteristics subscales were stable across the one-month interval. This information provides evidence that the screening tool provides accurate scores for the characteristics of FASD.

The characteristics assessed by the SFSP screening tool are useful in targeting specific needs for individual case planning, and the ratings based on the SFSP screening tool may help service providers decide on the appropriateness of need for specific services, interventions, and/or medical referral. An appropriate alcohol-related diagnosis helps families to set realistic expectations for their future, guides effective interventions and management, and helps individuals to ask for help. Research indicates that a screening tool is important for identifying individuals who may be affected by FASD; as Streissguth and O’Malley (2000) stated, “An appropriate diagnosis at any time is better than none at all” (p.182).

**Limitations**

As with any study, the present findings have limitations. The findings would generalize to a similar population of Ministry for Children and Family Development referred participants. It would be useful if the psychometric properties of the SFSP screening tool were further studied with a broader sample, to ensure that the results in this study can be replicated. A future study should attempt to gather data from a large and diverse group of parents suspected of FASD and to compare this data with that obtained from a random sample. As well, there was only confirmed maternal alcohol consumption for 18 completed SFSP screening tool forms, the reminder 47 completed SFSP screening
tool forms were not confirmed. Although the participants were instructed to rate a parent in which they were suspected or diagnosed with FASD, no confirmation was recorded.

The participants in this study were employees of the Ministry for Children and Family Development, and all but five participants worked in the field of child protection. All the participants volunteered to take part in the study. Data collected from one sub-population may create challenges for the research. These challenges include the possibility of one particular parent having been rated by two different participants. Due to the small number of participants and the nature of their work, the researcher did instruct the participants to keep their ratings confidential and to refrain from using identifying information on the SFSP screening tool.

A third challenge is that the participants specialize in the field of child protection and are not experts in recognizing the characteristics associated with FASD. It is important to note that the SFSP screening tool has construct validity but has not undergone testing for criterion, content, concurrent, or discriminate validity. It is possible that a parent who was rated by a participant has characteristics that are listed on the SFSP screening tool but has these characteristics because of another condition or an acquired brain injury, not FASD. Furthermore, based on time constraints and high case loads, social workers are limited to the amount of time that can be spent with each family, which in turn calls into question the worker’s ability to accurately rate the characteristics on the SFSP screening tool. Further testing is needed to evaluate the SFSP screening tool’s validity. Studies have not been completed to determine whether the tool succeeds in capturing the specific behavioural essence of FASD when compared with other developmental disabilities such as autism.
While acknowledging the limitations identified above, the researcher believes that generalization from this study is appropriate. The results provide a useful basis for the screening tool for screening individuals for FASD, to guide the referral process for a medical diagnosis, and to support in program planning.

Conclusion

This study was designed to investigate the psychometric properties of the SFSP screening tool. The key findings are that the 43-item SFSP screening tool represents a psychometric advancement in the area of FASD screening. The construct validity review of the Primary Characteristics subscale demonstrated that the characteristics listed are necessary for a screening tool for FASD. The SFSP screening tool items demonstrated moderate construct validity with exception of the five items. Overall, the internal consistency of the SFSP screening tool produced moderate results, indicating a practical tool for screening adults who may be suspected of FASD. The SFSP screening tool rating scale is an interpretable measure with stable and accurate estimates of the Primary and Secondary Characteristics associated with FASD. The rating scale developed for this tool yields reliable and sufficient results to be practical for meeting the purposes of program entry and for formulating a referral for a medical diagnosis of FASD. The test-retest reliability evidence indicated that the tool is moderately stable for screening for FASD. Participants gave feedback on ways the tool could be improved, including rating historical findings and reformatting the tool to include the rating scale on each page.

In summary, the findings are potentially important as they identify a tool that demonstrates reliable properties for screening adults for FASD. Furthermore, based on the purpose of the SFSP screening tool for program entry to the Structured for Success Project...
Screening for FASD

and for future referral for diagnosis, these results indicate that the SFSP screening tool would be a sufficient tool for these purposes. The SFSP screening tool is an important asset for individuals who work in the field of FASD. This screening tool will be a useful resource for practitioners, service providers, and for clients.

Recommendations

Implementing the following recommendations for the SFSP screening tool would improve the reliability of the screening tool. The recommendations are outlined separately for clinical and research recommendations.

Clinical Recommendations

1) The SFSP screening tool should be completed by the person who best knows the adult. In many cases this may not be the parent’s child protection worker; in those cases, it is recommended that the child protection worker collaborate with other service providers or family members to accurately complete the tool.

2) In the SFSP screening tool’s instructions section, it is recommended that a comment on the parent’s past history be included; in some cases, the rater may need to define a time-period (such as 5 years) for accurately answering the questions.

3) The SFSP screening tool should only be completed for an adult who’s mother was suspected or confirmed of maternal alcohol use prenatally.

Research Recommendations

1) It is recommended that a larger sample be tested for greater generalization.

2) It is recommended that a broader range of professionals who are knowledgeable in the area of FASD participate in further studies.
3) It is important that the rater knows the parent being rated fairly well before completing the SFSP screening tool.

4) It is recommended that further experts in the field of FASD evaluate the tool for the tool's content and discriminate validity.

5) To test the content and discriminate validity of the SFSP screening tool, it is recommended that a comparison study of individuals with a diagnosis of FAS/E to individuals who do not have any characteristics of FASD be implemented.

*SFSP Screening Tool Recommendations*

1) It is recommended that the number of examples provided on the SFSP screening tool be reduced. Removing excess examples may lessen confusion about the characteristic in question.

2) It is recommended that Item 22, "Talks Excessively" be removed from the Primary Characteristics subscale of the SFSP screening tool.

3) It is recommended that the rating scale be printed on each page of the screening tool.

4) It is recommended that the rater provide examples of the parent's characteristics that are rated.

5) It is recommended that a sum of the ratings (i.e., total score) be included at the end of the screening tool for each of the primary and secondary scales.
References


APPENDIX A

Structured for Success Project Overview
Structured For Success Project
Program Overview for Professionals

Introduction:
The Structured For Success Project (SFSP), is a family support program, designed to provide services to identified parents whose adaptive functioning and parenting capacity have been compromised by a combination of suspected or diagnosed FASD and/or other types of brain damage, including mental health issues and/or drug and alcohol misuse. The SFSP is a collaborative initiative between The Northern Family Health Society, Intersect Youth & Family Services Society, Ministry For Children and Family Development, Prince George Native Friendship Centre, The Northern Health Adult Mental Health Services and The Northern Health Addictions and Substance Use. These agency partners have come together to form a multidisciplinary team with the capacity to provide comprehensive, community based services in a wraparound support model. The SFSP recognizes that non-traditional intervention methods are required to meet the complex needs of families for whom historical approaches have been unsuccessful.

Program Design:
The SFSP uses a program model of environmental adaptation, which focuses on the environment surrounding the family to achieve changes, rather than changing the individual. The SFSP believes parents affected with FASD are willing to engage and learn strategies that maintain their families when program services provide a good match with the parent’s learning style and ability. Behaviours that have been developed as a coping strategy or defence and which are impacting the family negatively will serve as indicators for needed points of intervention. The SFSP’s interventions used to strengthen the family are based on a neurocognitive model of learning that utilizes concrete, experiential, kinaesthetic, context based teaching. The purpose of the interventions is to build a successful structure for the family that improves their well-being and
ability to parent. Case planning consists of individualized accommodations and interventions to meet ‘family driven’ goals reflecting their need for crisis planning, safety of children, life management skills, mental health services, addiction services, children’s mental health and parenting skills. We begin our work with families from a place of hopefulness, empathy, respect and mutuality and continue with a strength-based approach to achieve the desired outcomes.

**Criteria for Program Suitability:**

Up to twenty-five families can participate in the SFSP. Referrals are accepted from partner agencies through the designated SFSP staff member. Families who are accepted in the SFSP must meet the following criteria:

- The family has indicated their desire for services
- Sexual abuse is not the primary reason for referral
- Drug and/or alcohol use is sufficiently under control to permit participation.
- The parent’s/caregiver’s score on the SFSP screening tool indicates program suitability.
APPENDIX B

Information Letters and Consent Form
June 8, 2005

Karin Strong-boag
Community Services Manager
Ministry of Children and Family Development
1441 7th Ave
Prince George, BC
V2L 3P3

Dear Karin,

Re: Request to conduct research on Structured for Success Screening Tool.

I would like to have the permission of MCFD to conduct research investigating the reliability of the Screening for Success Screening tool. As you may know, the screening tool is being used to identify parents who may be affected by FASD and who may therefore be eligible for participation in the Structured for Success Project. The purpose of the proposed research is to further develop and evaluate the screening tool.

The proposed research is comprised of three studies which will be conducted in sequence. In Study 1, the screening tool’s content validity will be evaluated, as will the internal consistency of items on the tool. For Study 1, I am asking your permission to access completed screening tools that are on file for clients of the Structured for Success program. I do not need to contact the parents for any reason, and therefore do not plan to request parental permission to use the data for research purposes. Instead, I am asking your permission to use existing screening tool data for research purposes. No information that
might identify a parent would be extracted and all information that is extracted will be kept in strict confidence, as described below.

In Study 2, the test-retest reliability of the screening tool will be evaluated by asking social workers to complete screening tools about parents they know well. For this study, I am asking your permission to approach MCFD social workers to request that they participate in research. If you give your approval, I will obtain the informed consent of each social worker before they participate in this study. Each participating social worker will be asked to think of a parent from their caseload whom they know well and whom they suspect might be living with the consequences of prenatal exposure to alcohol. The social worker would be asked to complete the screening tool about that parent on two occasions, about one month apart. When completing the first screening, the social worker will be asked to provide a hint that will help them remember which parent they rated. The hint will be given back to the social worker at retest one month later. In this way, no information that might identify the parent need be requested. The information provided by the social worker would be kept in strict confidence, as described below. Completion of each screening tool should take approximately 30 to 40 minutes, for a total time commitment from each participating social worker of about 1 to 1.5 hours.

In Study 3, the inter-rater reliability of the screening tool will be evaluated by having two service providers rate the same parents at the same time, but independently. For this study, I am asking for your permission to approach staff at Structured for Success to request that they participate in research. If you give your approval, I will obtain the informed consent of staff at Structured for Success prior to their participation in the study. Each staff member will be asked to rate up to 10 families. No information that might
identify the parent need be requested. The parents’ identity will be concealed. At
approximately 30 minutes per screening tool, the total time commitment per staff member
will be 5 hours.

All information collected will be kept in the strictest confidence. All families and
social workers will be identified by numerical code only. All data will be kept on a secure
computer and only the research team will be able to access the data by use of passwords.
For Study 1, numeric data will be extracted from client files by me, in my capacity as a
staff member of the Structured for Success program. Those screening tools will remain on
the client’s file at Structured for Success. For Studies 2 and 3, screening tools will be
completed purely for research purposes and will be kept in a secure locked cabinet in a
locked research laboratory controlled by Dr. Cindy Hardy. One year after completion of the
study, the screening tools completed for Studies 2 and 3 will be destroyed. All reports of
the findings will be presented in grouped form and no individual will be identifiable. A
report of the study’s findings will be provided to you and to all participants upon request.

I would like to conduct the proposed research through the summer and fall of 2005.
This project must be approved by UNBC Ethics Review Board before data collection can
begin. UNBC will not give final approval to the project until I can show them a letter of
approval from you on behalf of MCFD. I will contact within a week to answer any
questions you may have.

Sincerely,

Chantelle Wilson

Encl.
Screening for FASD 100

Masters Thesis proposal

UNBC Ethics Review Approval Form

Study Information Letter – Test-retest reliability

Psychology Program

Researcher’s Name: Chantelle Wilson

Address: 3333 University Way Prince George, British Columbia, Canada V2N 4Z9

Phone No: (250) 960-5814 Email: chantelle.wilson@northernhealth.ca

Supervisor Name: Cindy Hardy, Ph.D., R.Psych

Title of Project: Screening for Success: Evaluating reliability for a Screening tool for FASD in adulthood.

Type of Project: Thesis

Date:

Dear Service Providers,

Thank you for your consideration in this project; you are being asked to participate in the research of investigating the reliability of the Screening for Success Screening tool. This screening tool is intended to screen parents that may be affected by Fetal Alcohol Spectrum Disorder (FASD). If you agree to take part in the study, you will be asked to complete two screening tools based on a parent you know well and whom are suspected or known to have been exposed to alcohol prenatally during a 1-month period. The parent’s information will remain confidential and no identifying information will be asked for.

What is the purpose of this Study?

The purpose of this study is to determine if the screening tool developed is reliable for identifying parents that may be affected by FASD.
Who is being asked to take part and what will they do?

Social Workers and Family Workers are being asked to participate in this study, the completion of the screening tool should approximately take 30-40 minutes to complete.

When and where will the study take place?

The completion of the screening tool will take place at your convenience between the summer and fall of 2005.

Explanation of Procedures

If you agree to take place in the study, the following will occur:

- you will be asked to complete an initial screening tool on a parent you know well and whom are suspected or known to have been exposed to alcohol prenatally
- you will be asked to provide a “hint” to remember what parent you rated previously as to ensure you are rating the same parent and to ensure confidentiality of the parent. I will provide you with the hint before the second screening tool is completed.
- After 1-month time, you will be asked to complete a second screening tool on the same parent.

What are the risks/or discomforts of the study?

There are no known risks or discomforts associated with this study other than the time that is required to complete the two screening tools.

What are the benefits of the study?
The benefits seen from this research include the development and evaluation of the screening tool. After the research is completed and if the tool is found to be a reliable measure, it will assist in the ability to identify parents who may benefit from programs/services designed for individuals affected by FASD. An additional benefit is to capture the adaptive functioning difficulties of individuals with FASD. Furthermore, the tool can be used for the parents to take to the family doctor for a referral for diagnosis and for the parents to be able to understand their cognitive difficulties in plain English.

*Can I withdraw from the study at anytime?*

Your participation in this study is entirely up to you. If you agree to participate, your participation is voluntary and you are free to change your mind and withdraw from the study at anytime. If you choose to leave the study, any information collected will be withdrawn from research data. You do not have to give any reason for not participating or for withdrawing from the study.

*Is the study confidential?*

All information collected will be kept in the *strictest confidence*. You will be identified by numerical code only. All data will be kept on a secure computer and only the research team will be able to access the data by use of passwords. The completed screening tools will be kept in a secure, locked cabinet in a locked research laboratory controlled by Dr. Cindy Hardy. When the study is completed, a brief written report of the results will be provided to you. There will be no information released or printed that will disclose your identity. One year after completion of the study, the completed screening tools will be destroyed by shredding all copies.

*Opportunity to ask questions:*
You may ask any questions regarding this research, before, during and/or after your participation. Any questions you have before agreeing to participate will be answered prior to your participation.

Rights and Complaints:

If you have any complaints about your participation, or have any questions regarding this study, you may direct any complaints to the Vice President of Research at UNBC, phone (250) 960-5820. Thank you for your interest in this project. Please keep this letter for your records.

Sincerely,

Chantelle Wilson
Informed Consent Form

Test-retest Reliability

I understand that I am being asked to participate in completing two screening tools on a family that I know well and the estimated time will be 20-30 minutes.

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I understand that all information will remain confidential and that the family’s identifying information is not required.

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Do you understand that you are free to participate or withdraw from this study at any time?

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I understand that all information collected will be kept on a secure computer which will be password protected. One year after completion, all materials will be destroyed.

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I understand that all information collected will not have names of the parents or any identifying information on them and no information will be printed or released that would identify personal identity.

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I am aware that all information collected will be used only by the research team and that no other person will have access to them.

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Any risks or benefits of my participation have been explained to me to my satisfaction.

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Any questions that I had regarding this study have been answered to my satisfaction. I will receive a signed copy of this consent form.

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Declaration of Consent

This study was explained to me by: ________________________

Print Name

I agree to take part in this study:

____________________________________________________

Signature of Research participant Date

Print Name of Research participant

______________________________

Signature of Witness Date

Print Name of Witness

I believe that the person signing this form understands in this study and voluntarily agrees to participate.

______________________________

Signature of Investigator Date
APPENDIX C

Institute of Medicine diagnostic criteria for fetal alcohol syndrome and alcohol-related effects
Diagnostic criteria for fetal alcohol syndrome and alcohol-related effects

Fetal alcohol syndrome (FAS)

1. FAS with confirmed maternal alcohol exposure*
   
   A. Confirmed maternal alcohol exposure*
   
   B. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum and flat midface)
   
   C. Evidence of growth retardation, as in at least one of the following:
      
      - low birth weight for gestational age
      - decelerating weight over time not due to nutrition
      - disproportional low weight-to height ratio
   
   D. Evidence of central nervous system neurodevelopmental abnormalities, as in at least one of the following:
      
      - Decreased cranial size of birth
      - Structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)

   Neurologic hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

2. FAS without confirmed maternal alcohol exposure
   
   B, C, and D as above
3. Partial FAS with confirmed maternal alcohol exposure

A. Confirmed maternal alcohol exposure*

B. Evidence of some components of the pattern of characteristic facial anomalies

Either C or D or E

C. Evidence of growth retardation, as in at least one of the following:

1. low birth weight for gestational age
2. decelerating weight over time not due to nutrition
3. disproportional low weight-to-height ratio

D. Evidence of CNS neurodevelopmental abnormalities, e.g.,

1. Decreased cranial size at birth
2. Structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
3. Neurologic hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

Evidence of a complex pattern of behaviour or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone: e.g., learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention or judgment.
4. Alcohol-related birth defects (ARND)

Congenital anomalies, including malformations and dysplasias

Cardiac  
- Artial septal defects
- Aberrant great vessels

Ventricular septal defects  
- Tetralogy of Fallot
- Skeletal

Hypoplastic nails  
- Clinodactyly
- Shortened fifth digits

Pectus excavatum and carinatum  
- Radioulnar synostosis
- Klippel-Feil syndrome

Flexion contractures  
- Hemivertebrae
- Camptodactyly

Scoliosis  
- Renal
- Aplastic, dysplastic,

Ureteral duplications  
- Horseshoe kidneys
- Hydronephrosis

Ocular  
- Strabismus
- Refractive problems

Retinal vascular anomalies  
- Auditory
- Conductive hearing loss

Neurosensory hearing loss  
- Other

Virtually every malformation has been described in some patient with FAS. The Etiologic specificity of most of these anomalies to alcohol tertogensis remains uncertain.

5. Alcohol-related neurodevelopmental disorder (ARND)

Presence of A or B or both.

A. Evidence of CNS neurodevelopmental abnormalities, as in any one of the following:

1. Decreased cranial size at birth

2. Structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)

3. Neurologic hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination
4. Evidence of a complex pattern of behaviour or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone: e.g., learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention or judgment.

* A pattern of excessive intake characterized by substantial, regular intake or heavy episodic drinking. Evidence of this pattern may include frequent episodes of intoxication, development of tolerance or withdrawal, social problems related to drinking, legal problems related to drinking, engaging in physically hazardous behaviour while drinking or alcohol-related medical problems such as hepatic disease.

APPENDIX D

4-Digit Diagnostic Code criteria for FASD
<table>
<thead>
<tr>
<th>Rank</th>
<th>Growth deficiency</th>
<th>FAS facial phenotype</th>
<th>CNS damage or dysfunction</th>
<th>Gestational exposure to alcohol</th>
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</thead>
<tbody>
<tr>
<td>4</td>
<td><strong>Significant</strong></td>
<td><strong>Severe</strong></td>
<td><strong>Definite</strong></td>
<td><strong>High risk</strong></td>
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<td>Height and weight below 3rd percentile</td>
<td>All 3 features: PFL 2 or more SDs below mean Thin lip: rank 4 or 5 Smooth philtrum: rank 4 or 5</td>
<td>Structural or neurologic evidence</td>
<td>Confirmed exposure to high levels</td>
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<tr>
<td>3</td>
<td><strong>Moderate</strong></td>
<td><strong>Moderate</strong></td>
<td><strong>Probable</strong></td>
<td><strong>Some risk</strong></td>
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<tr>
<td></td>
<td>Height and weight below 10th percentile</td>
<td>Generally 2 of the 3 features</td>
<td>Significant dysfunction across 3 or more domains</td>
<td>Confirmed exposure. Level of exposure unknown or less than rank 4</td>
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<tr>
<td>2</td>
<td><strong>Mild</strong></td>
<td><strong>Mild</strong></td>
<td><strong>Possible</strong></td>
<td><strong>Unknown</strong></td>
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<tr>
<td></td>
<td>Height and weight below 10th percentile</td>
<td>Generally 1 of the 3 features</td>
<td>Evidnece of dysfunction, but less than rank 3</td>
<td>Exposure not confirmed present or absent</td>
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<td><strong>None</strong></td>
<td><strong>Absent</strong></td>
<td><strong>Unlikely</strong></td>
<td><strong>No risk</strong></td>
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<tr>
<td></td>
<td>Height and weight at or above 10th percentile</td>
<td>None of the 3 features</td>
<td>No structural, neurologic r functional evidence of impairments</td>
<td>Confirmed absence of exposure from conception to birth</td>
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APPENDIX E

Citations for the SFSP Screening Tool
Table E1
Citations for the SFSP Screening Tool

<table>
<thead>
<tr>
<th>Primary Characteristics</th>
<th>Empirical Resources</th>
<th>Professional Resources</th>
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<td>Primary Characteristics</td>
<td>Empirical Resources</td>
<td>Professional Resources</td>
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<td>----------------------------------------------------------------------------------------</td>
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<td>------------------------</td>
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<tr>
<td>17. Has Difficulty with Concepts such as Ownership, Honesty</td>
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<td>McCreight, B. 1991.</td>
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APPENDIX F

Descriptive and Reliability Statistics for Items on the SFSP Screening Tool
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